

COMING TO TERMS: SIX MOTHERS' EXPERIENCES PARENTING
INFANTS AND TODDLERS WITH DISABILITIES

By

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By

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Chair: Vivian I. Correa
Major Department: Special Education

In this study of how 6 mothers learned about, came to understand, and responded to the evolving realities of having a child with disabilities, I collected information that can increase professionals' understanding of both successful and inadequate family-professional interactions. I selected mothers for this study because mothers typically assume the primary interface between a young child and developmental services. Each met the exclusionary criteria of being a mother of a child, birth through age 2, who was receiving early intervention services under the auspices of the state of Florida's Early Intervention Program, under Part C of the Individuals with Disabilities Education Act. In interviews I investigated (a) receiving diagnoses, (b) employing coping mechanisms and accessing support systems, and (c) establishing parent-professional

relationships. I conducted the study in a mid-sized rural district of Florida, interviewing 6 mothers three to five times in their homes. Additionally, I observed parent-professional interactions between participants and 7 service providers (occupational therapists, physical therapist, speech-language pathologists, and a developmental specialist). I then conducted interviews with the service providers investigating their perceptions of family-centered practices.

Data revealed that all 6 mothers cycled through the sub-stages of (a) becoming aware of a child's diagnosis of disability; (b) discovering, seeking, and finding services; (c) enrolling in services; (d) learning the system; and (e) looking back. Each mother used at least one palliative coping technique; all used a combination of adaptive coping techniques including reframing, searching for information, and turning to religion. Mothers often experienced difficulty discovering available services and felt that medical professionals were reluctant to make referrals. Mothers expressed the most satisfaction with service providers who practiced family-centered methods. However, service providers said they received little training in this area. It does no good for agencies to have family-centered philosophies if policies and service providers do not consistently reflect and implement this approach. On going and pre-professional training are needed to cultivate understanding of family-centered methods.

CHAPTER 1 INTRODUCTION TO THE PROBLEM

Intraduction

Anticipating the birth of a new baby is a joyful experience for most parents as they envision the personality, physical attributes, and potential of the new family member. Unanticipated stressors challenge parents when a child is born with or later acquires a disability (Beckman, 1991; Rodrigue, Margan, & Gefken, 1990; Turnbull & Turnbull, 2001; Wilgash, 1990). According to Diamond (1994), many factors contribute to the stress parents experience. Possible stressors include increased financial burdens, extraordinary time demands, actual or perceived stigmas associated with the child's disability, behavior management difficulties, social isolation, and pessimism about the future (Diamond, 1994; Dunst, Trivette, & Deal, 1988; Raver, 1999; Turnbull & Turnbull, 2001). Parents of infants and toddlers with disabilities perhaps face the greatest stress if they cannot easily assess accurate information from empathetic professionals willing to provide family-centered services (Judge, 1998).

Parents of infants and toddlers with disabilities may find that they and their child are eligible for services through the Early Intervention

Program under the Individuals with Disabilities Education Act (IDEA). This program provides for comprehensive services for infants and toddlers (birth through age two) with special needs and their families (Education for All Handicapped Children Act Amendments of 1986). Although the nature of early intervention services across states varies considerably due to each state's interpretations of the law (Hebbeler et al., 1999), most services for infants and toddlers with special needs and their families have the following principal program objectives:

1. To provide information, support, and assistance to families dealing with the needs associated with their child's development.
2. To build parents' confidence as the primary facilitators of their child's development and as the principal advocates for their child.
3. To promote interactions between family members that encourage mutual feelings of competence and enjoyment. (Raver, 1999, p. 4)

In the past, infants and toddlers with disabilities and their families were primarily served under IDEA using a professionally based, child-oriented model. That is, the services the child received were determined by service-providers without or with little regard for the preferences and priorities of the family (Trivette, Dunst, Boyd, & Hamby, 1995). Since the mid 1990s, more emphasis is now being placed on family-centered services. As delineated by the law, a major goal of early intervention is to "enhance the capacity of families to meet the special needs of their infants and toddlers with disabilities" (Education for All Handicapped

Children Act Amendments of 1986). According to legal mandate, families have the right and responsibility to be involved in determining the services for their child.

A family-centered perspective posits that the ultimate goal of early intervention is to enable and empower families so that services result in a strong and supported family. The extent to which families' needs are met makes a family more competent and better able to mobilize resources, which in turn promotes child, parent, and family functioning (Dunst, Trivette, & Deol, 1988). Bailey, Buysse, Edmonson, and Smith (1992) identify the following assumptions of family-centered service delivery:

1. Children and families are inextricably intertwined. Intentional or not, intervention with children almost invariably influences families; likewise, intervention with and support of families almost invariably influences children.
2. Involving and supporting families is likely to be a more powerful intervention than one that focuses exclusively on the child.
3. Family members should be able to choose their level of involvement in program planning, decision-making, and service delivery.
4. Professionals should attend to family priorities for goals and services, even when those priorities differ substantially from professional priorities. (pp. 299-300)

Statement of the Problem

Although researchers have emphasized the need to provide family-centered services, services often continue to focus on only the child's needs rather than viewing the needs of the family as a whole. For families of very young children, medical professionals in hospital settings often notify the parents of the child's diagnosis. Some diagnoses may even be

made before the baby's birth. Because these early diagnoses are often accompanied by concerns for the child's health, those medical issues may override considerations of family needs. Yet service provision to the child is only one aspect of family-centered services. Providing supports for families is also an integral part of early intervention program services. Interventionists should help parents develop priorities and goals for the entire family by determining appropriate services so that parents become empowered to access future services for themselves and their child. Families may find it difficult to determine and adjust to their own emotional needs during the period following initial diagnosis because the child's medical and early developmental needs demand time and financial resources (Beckman, 1996; Howard, Williams, Port, & Lepper, 2001). These concerns may take precedence over parents' own needs (Beckman, 1996; Dunst, Trivette, & Deol, 1988; Turnbull & Turnbull, 2001).

One factor that may influence the family's priorities and goals is their individual personal experiences when they first learn their child has a disability. Researchers have barely begun to examine the personal experiences of parents as they first learn of the diagnosis of disability and examine their capacity to function as parents of a child with a disability. The limited empirical evidence of families' initial journeys with disability may contribute to professional disregard of the trials families may encounter. Additional research on parents' experiences with the early

intervention program can provide interventionists with a strategy for supporting parents and may provide additional information for the development of family-centered services. Feedback from parents regarding the types of support determined useful in coping with the stress surrounding children's disabilities is necessary in order to guide the behavior of service providers as well as influence systemic change by providing information that facilitates family-centered services.

Though families are acknowledged as vital to the success of early intervention, many professionals still concentrate only on the child's needs. If professionals knew more about the experience of parents as they cope with a young child's diagnosis of disability, they could better determine effective supports for families and facilitate the provision of family-centered services (Beckman, 1996; Dunst, Trivette, & Deal, 1988; Haward, Williams, Parl, & Lepper, 2001; Roberts, Rule, & Innacenti, 1998; Turnbull & Turnbull, 2001). Examining individual family experiences would increase a professional's understanding of both successful and inadequate family-professional interactions.

Purpose of the Study

The goal of the study was to find out how 6 mothers learned about, came to understand, and responded to the evolving realities of having a child with disabilities. I selected mothers for this study because mothers typically assume the primary interface between a young child and

developmental services (Govideo-Payne & Stoneman, 1997). While exploring the experiences of these 6 mothers of infants or toddlers with disabilities, I investigated several areas that relate to mothers of young children with disabilities including (a) receiving diagnoses, (b) employing coping mechanisms and accessing support systems, and (c) establishing parent-professional relationships.

My first area of investigation involved concerns that arose as families received an initial diagnosis of their child's disability. I asked mothers to describe their experience during the initial diagnosis of their child's disability. A crucial component of my investigation was the interaction between mothers and the professionals delivering the diagnosis. Factors related to this interaction included (a) the manner in which the diagnosis was delivered, (b) the information provided relative to the diagnosis, and (c) the supports offered to assist the mother following the diagnosis.

Furthermore, I examined the interplay between a mother's ability to cope with disability-related stressors and the supports that existed for that mother. I asked mothers to describe the coping mechanisms they used during the initial period of diagnosis and intervention. In addition, I examined supportive relationships, including those from both natural and more formal supports, to determine what the mothers perceived as helpful to them as they faced disability-related stressors.

The final area I investigated involved the establishment of parent-professional relationships as the mothers accessed both medical and early intervention program services for their child. I explored how mothers became aware of the early intervention program and what assistance they received from both medical and developmental service providers in accessing services. I questioned how mothers evaluated services, and identified service providers' positive and negative qualities and methods.

My study provides the field of early intervention with insights into the experiences of mothers of young children with disabilities. I examined (a) initial diagnosis, (b) coping and supports, and (c) parent-professional relationships as they relate to mothers' individual experiences. My study provides professionals with a better understanding of what mothers perceive as appropriate and effective intervention strategies professionals may utilize when working with families. This increased awareness of the issues identified by the 6 mothers in my study serves as a foundation for future research examining the crucial period of early adjustment for mothers to a child's disability.

Theoretical Foundation

I based my study on established family systems theory, applying two perspectives. The first, family systems framework (Turnbull & Turnbull, 2001; Turnbull, Summers, & Bratherson, 1984), represents the interactive and dynamic qualities of families. The second, social ecology theory

(Bronfenbrenner, 1979), demonstrates the relationship of the family to the larger social environment. From the perspective of these theories I studied how families of children with disabilities interact under stress and how service providers and other support systems can help them cope. I introduce these theories below and provide further detail in Chapter 2.

Family Systems Framework

The family systems framework (Turnbull & Turnbull, 2001; Turnbull, Summers, & Brotherson, 1984) addresses four components of family life: (a) family characteristics, (b) family interaction, (c) family functions, and (d) family life cycle. Family characteristics include the personal characteristics of family members as well as features of family size and form, socioeconomic status, and cultural background. Family interaction examines perspectives of family configurations as well as the adaptability and cohesion of the family. Family functions comprise tasks or activities that are performed to meet the wants and needs of the family. Categories included in this component are affection, self-esteem, spirituality, economics, daily care, socialization, recreation, and education. The influence of individual family members upon family functions, whether positive, negative, or neutral, is also of consideration. Family life cycle describes how a family changes as it moves through different stages, especially how it handles transitions.

Social Ecology Theory

Bronfenbrenner's (1979) social ecology theory links the family environment to human development. This theory proposes that individuals act within several ecosystems. Within Bronfenbrenner's model are four ecosystems: the microsystem, mesosystem, exosystem, and macrosystem. The microsystem includes any immediate contexts in which the individual is an active participant. The mesosystem consists of the connections between two or more settings in which the individual participates. Exosystem contexts have a direct impact upon the individual even though the individual is never actively involved in those contexts. Finally, the macrosystem involves beliefs and ideologies that exert influence over the individual and family.

Summary of Theoretical Foundation

My study relied heavily on perspectives from both of these theoretical models of family systems, which emphasize the influence of individual family members upon the experience of the entire family. Using qualitative methodology, I employed both models of family systems theory to examine (a) the direct influence a child with disabilities has on a mother adapting to the child's disability and (b) the mothers' perceptions of the impact of a child with a disability upon the family system.

Significance of the Study

Introduction

All 6 women in my study were the mothers of infants and toddlers, allowing me to focus on a crucial time period for families of children with disabilities. This time period warrants greater attention since children receiving early intervention services experience more positive development, as does the family support system (Guralnick, 1997). Yet, research has focused on older children and those of countries other than the United States. What research does exist utilized predominately quantitative research methods or questionable qualitative data analysis procedures. My study is based on interviews and observations of how mothers of children with disabilities interact under stress and how service providers and other support systems can help them cope.

Overview of the Literature

The relevance of family systems theory as it pertains to families of children with disabilities is evident when examining the literature. A substantial number of studies have investigated the impact of disability upon the family. These studies analyzed issues families faced when (a) receiving the initial diagnosis of disability (Helm, Miranda & Chedd, 1998; Baxter, Cummins, & Pallack, 1995; Radrigue, Margan, & Gefken, 1990), (b) coping with the diagnosis and establishing a support network (Judge, 1998; Atkinson et al., 1995; Hanline & Daley, 1992), and (c) establishing

parent-professional relationships (Judge, 1998; Quine & Rutter, 1994; Slaper & Turner, 1993b). Together, these studies substantiate the significance of family stress when faced with disability issues.

Receiving the initial diagnosis of disability. The initial diagnosis of disability has been acknowledged as being very stressful on parents (Baxter, Cummins & Pollack, 1995; Slaper & Turner, 1993a). The literature identifies three attributes that may affect parents during this period. These attributes are (a) diagnosis during the prenatal period, (b) type and severity of the disability, and (c) uncertain diagnoses. The literature indicates that parents experience stress during this time period, though the types and degrees of stress varies widely (Baxter, Cummins, & Pollack, 1995; Hanline & Daley, 1992; Helm, Miranda, & Chedd, 1998; Judge, 1998; Quine & Rutter, 1994; Slaper & Turner, 1993a). It is important for service providers to listen to family members in order to determine the specific ways that disability issues are stressing them. Available supports may mediate parental stress at this time.

Employing coping mechanisms and accessing support systems. The variable potential for families to respond to stressors related to raising a young child with disabilities has led many researchers to investigate coping strategies and support systems. Coping has been defined as "cognitions and behaviors used by the individual in evaluating stressors and in initiating activities with the aim of decreasing their impact"

(Margolit, Raviv, & Ankonino, 1992, p. 202). Within the coping literature, two major categories of coping strategies emerged: (a) adoptive coping strategies, which change the source of stress or the individual; and (b) palliative coping strategies, which are emotion focused (Thompson, Zenman, Fanurik, & Sirotkin-Roses, 1992). Researchers have investigated successful coping from many perspectives including family functioning, adaptation to disability, and ethnic variables.

Additionally, available support systems can be an important factor affecting how families of a child with disabilities experience stress. Support systems can be divided into three subsystems (Cooley, 1994), (a) natural supports, (b) informal supports, and (c) formal supports. Some researchers have investigated the interaction between families' ability to cope and their support systems. I also found evidence in the literature of different subsystems of support being more important to families at crucial times, such as initial diagnosis or when the child enters school. Many favorable conditions can result from diagnoses during this period as well. Children receiving early intervention services experience more positive outcomes. As Guralnick (1997) explains, "the early years constitute a unique opportunity for influencing child development and supporting families, an opportunity that may well maximize long-term benefits for all concerned" (p. 3). Positive relationships between service providers and families often

set the stage for successful future relationships. Differences are also evident between the types of support needed by fathers and mothers.

Establishing parent-professional relationships. The early interaction between parents and professionals, especially at the time of initial diagnosis of disability, can influence future parent-professional relationships (Hasnat & Graves, 2000). Of vital importance to families is the perceived concern from professionals and the amount of information professionals offer (Slaper & Turner, 1993b). Communication, as demonstrated through both professional concern and willingness to share information, is also important to families in subsequent interactions with professionals (Quine & Rutter, 1994).

Opportunities for collaborative parent-professional relationships may be presented as families and professionals develop the Individual Family Service Plan (IFSP) and work together to evaluate the child's progress (Raver, 1999). Collaboration is defined as "the dynamic process of families and professionals equally sharing their resources in order to make decisions jointly" (Turnbull & Turnbull, 2001, p.50). Judge (1998) found that positive parent-professional interactions empowered families by involving them in decision-making. Conversely, professionals who did not employ family-centered methods disempowered families' decision-making process.

Limitations of the Literature

Based upon the goal of my study, determining mothers' own perspectives of their children's diagnosis and subsequent interventions, my examination of the literature reveals some significant weaknesses. These concerns and limitations fall under three categories. First, the majority of studies were conducted entirely or predominantly on older children. Second, although limited studies involved qualitative data collection methodology, most applied quantitative data analysis procedures including rating data and applying statistical procedures to interview and observational data. Finally, many of the studies I examined were conducted in countries outside the United States.

Summary of Study Significance

My study is significant in two ways. First, I focus exclusively on mothers of infants and toddlers with disabilities. Mothers are traditionally viewed as the gatekeepers of information regarding a child with disabilities (Bailey, Skinner, Rodriguez, Gut, and Carrea, 1999). This period is important because the initial diagnosis of disability is one of the most stressful times for parents (Baxter, Cummins & Pallack, 1995; Sloper & Turner, 1993a). Research shows that not every family reacts the same way, but all utilize palliative and/or adaptive coping mechanisms. This study illuminates how these coping mechanisms are first employed, how service providers can help, and what additional support systems are beneficial.

This focus is especially important to the study of parent-professional relationships since the initial interactions, especially at the time of diagnosis, appear to influence subsequent parent-professional interaction. In addition, early intervention during this time increases the long-term development of the child and family.

Second, my study is significant because of its reliance on qualitative research methodology, which allowed participants to describe their experiences in their own words rather than choose from a researcher's categories. Mothers responded to semi-structured interview questions centered on their perceptions of what was occurring to them during the actual periods of early diagnosis of disability and access of early intervention services, rather than years later. By allowing these mothers to report their own perceptions of the reality of caring for a child with disabilities, this study raises awareness of what issues are important to mothers as they (a) receive initial diagnosis, (b) employ coping mechanisms and access support systems, and (c) establish parent-professional relationships.

Research Questions

The research questions central to this study were developed from the perspective of family systems theory and were intended to elicit qualitative data concerning the effects on mothers during the first 3 years

of caring for a child with developmental disabilities. They were the following:

1. How did these mothers respond to the initial disability diagnosis?
2. What did mothers perceive to be the long- and short-term future implications of the diagnosis for their child, their families, and themselves?
3. What types of support did mothers seek, find, and receive for their child, their families, and/or themselves?
4. What qualities did mothers value in professionals?
5. What changes did mothers suggest to early intervention services?

In the following chapter I elaborate on the theoretical foundation and former research that provide the background and foundation for my study.

CHAPTER 2 REVIEW OF THE LITERATURE

Introduction

In this chapter, I review relevant literature on initial diagnosis, coping strategies and support systems, and parent-professional interactions experienced by families with infants and toddlers with disabilities. I first detail the theoretical foundation of this research. My review of current research follows as examined from three different activities. In the first activity, receiving the initial diagnosis, I examine literature addressing the process of delivering the diagnosis of disability as well as the reaction of parents to the diagnosis. Second, I review research on the coping strategies and support systems of families encountering disability issues. This literature is not limited to the time of initial diagnosis, but addresses family coping with the ongoing stressors associated with a child's disability and the supports that may assist in this endeavor. Finally, I examine the literature on parent-professional relationships. I discuss parent-professional interactions at the time of initial diagnoses and the manner in which subsequent parent-professional relationships are developed.

Theoretical Foundation

I organized my findings around family systems theory. A premise of family systems theory is that a singular event, such as the birth of a child with a disability, affects subsequent events and interactions as well as the individuals involved in those events and interactions. I applied two perspectives of family systems theory to my study. The first, family systems framework, (Turnbull & Turnbull, 2001; Turnbull, Summers, & Bratherson, 1984) focuses on the interactive and dynamic qualities of families. The second, social ecology theory (Bronfenbrenner, 1979) demonstrates the relationship of the family to the environment.

Family Systems Framework

Turnbull and colleagues proposed a family systems framework for examining family relationships (Turnbull & Turnbull, 2001; Turnbull, Summers, & Bratherson, 1984). This model focuses on four components of the family: (a) family characteristics, (b) family interaction, (c) family functions, and (d) family life cycle. The model is schematically represented in Figure 2.1.

Family characteristics. Included in family characteristics are such features as the family size and form, socioeconomic status, the geographic region in which the family lives, and the family's cultural background (Turnbull & Turnbull, 2001). In addition, the personal characteristics of each family member need to be considered. The

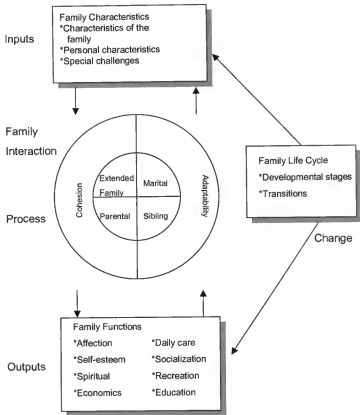


Figure 2.1 Family Systems Framework (Turnbull, Summers, & Brotherson, 1984). Used with permission.

personal characteristics of a family member who has special needs often affects the overall characteristics of the family. Other personal characteristics may include the mental and physical health and coping

styles of individual family members as well as the characteristics of the child's disability (Turnbull & Turnbull, 2001). A final consideration of family characteristics is any special challenge such as the influence of poverty, substance abuse, and parental disability factors.

Family interaction. The family systems framework identifies four different family subsystems when examining family interactions. The marital subsystem involves interactions between spouses or significant others. The parental subsystem consists of parent and child interactions. Thus there may be several parental subsystems within a family, determined by the number of children in the family. The configuration of the family is a consideration of parental subsystems. Some families consist of stepparents, adoptive parents, or foster parents. Sibling subsystems are interactions between children. Once again, the family configuration must be considered. The final subsystem consists of interactions with extended family. Included in this subsystem are not only nuclear relatives, but also others who are regarded by the family as relatives.

Two other aspects, cohesion and adaptability, may influence family interactions. These elements, adapted from Olson, Russell, and Sprenkle (1983) refer to the quality of family relationships. As explained by Turnbull and Turnbull (2001), "the degrees of cohesion and adaptability in a family describe the ways that subsystems interact and the nature of the boundaries among family subsystems and among family members and

nanmembers" (p. 124). Cohesion, the emotional bonding among family members, operates on a continuum ranging from enmeshment to high disengagement.

Adaptability refers to a family's ability to adjust to change. Like cohesion, this element consists of a range of behaviors. At one end of the continuum are families that are highly controlled or rigid. These families contrast with those families that are more flexible, or even chaotic. The key aspect in both cohesion and adaptability is the ability to maintain balance (Becvar & Becvar, 1996).

Family functions. The third component of the Turnbull model is family functions. Family functions are tasks or activities that are performed to meet the wants and needs of the family. Categories of activities included in this component are affection, self-esteem, spirituality, economics, daily care, socialization, recreation, and education. These categories are not exclusive of each other, and advantages or disadvantages from one category may affect how the family functions within another category.

The second interaction relative to family functions is the way individual family members, including a child with a disability, influence each of the family functions. The effect of this influence may be positive, negative, or neutral. For example, some families have acknowledged the positive influence in describing their child with a disability as a major

catalyst for enhancing family love (Behr & Murphy, 1993; Summers, Behr, & Turnbull, 1989). Conversely, some families may see a negative impact resulting from the economic demands of a child with a disability including transportation to service providers, medical care, and personal care.

Family life cycle. The final component of this model is the family life cycle, which explains how a family changes over time as it moves through different life-cycle stages. An additional critical element of the family life cycle is the aspect of transition. When a family moves from one stage to the next, it is said to be in transition. A recognized transition for families with infants and toddlers with disabilities occurs when their young children turn 3 and move from the early intervention program into services provided by the local education agency.

Each of the components of the family systems framework (family characteristics, family interaction, family functions, and family life cycle) addresses issues that are encompassed within the parameters of the individual family. Yet there must be a recognition that the family does not exist in isolation from factors external to the family. An appreciation for the influence of these factors is promoted through social ecology theory.

Social Ecology Theory

Bronfenbrenner's (1979) seminal work on social ecology theory links the family environment to human development. According to Bronfenbrenner, the ecological environment "is conceived as a set of

nested structures, each inside the next, like a set of Russian dolls" (p. 3).

This theory supports the concept of individuals acting within several ecosystems. Bronfenbrenner proposed that the way an individual views one's own capacity to function in various ecosystems is influenced by factors that may make demands, produce stress, or provide support upon that individual.

Within Bronfenbrenner's model are four ecosystems, each which functions at an increasing distance from the individual. These ecosystems, the microsystem, mesosystem, exosystem, and macrosystem are illustrated in figure 2.2. Important to my study was the examination of the families' microsystem, exosystem, and macrosystem components and the mesosystemic connections between them.

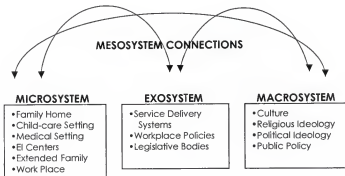


Figure 2.2 Social Ecology Theory Applied to Early Intervention

Microsystem. The microsystem includes the immediate context in which an individual lives. For mothers of infants and toddlers with disabilities, the predominant microsystem may be the context of the family home (Berry & Hardman, 1998). There are, however, other microsystems that may exert powerful influences. These may include childcare settings, medical settings, early intervention centers, workplace, and extended family members (Gabarinio & Abramowitz, 1992).

Mesosystem. Mesosystems consist of the connections or interrelationships among two or more settings in which an individual participates. Berry and Hardman (1998) propose that for families of children with disabilities, the success of mesosystem connections may depend upon parents' "communicative and cognitive abilities, self-confidence, personality, and ability to handle stress" (p. 111). They caution, however, that these connections are bi-directional. Professionals must also determine which strategies promote stable mesosystem connections.

Exosystem. Exosystems are contexts in which the individual is not "an active participant but in which events occur that affect, or are affected by, what happens in that setting" (Bronfenbrenner, 1979, p. 237). For mothers of young children with disabilities, possible exosystems include administrative bodies for early intervention agencies, childcare policy groups, employment policymakers, and state and national legislative

bodies. In this study, I examine how these same contexts may support or challenge a mother's ability to face the day-to-day realities of parenting a child with a disability.

Macrosystem. Dunst, Trivette, and LaPointe (1994) assert that macrosystems refer to relationships that "directly and indirectly link micro-, meso-, and exosystems and the degree to which consistencies [emphasis in original] in beliefs and ideologies across settings have cumulative and interactive effects on people's behaviors" (p. 22). Included in macrosystems are society's culture, as well as religious and political ideology and policies (Garbarino & Abramowitz, 1992). Public policy is often influenced by a society's culture. For example, both the Individuals with Disabilities Education Act (IDEA) and the American's with Disabilities Act (ADA) are political policies that were influenced by society. The influences of these laws are now interactive in that they impact society.

Linkages to Theoretical Perspectives

Both Turnbull, Summers, and Brotherson's family systems framework and Bronfenbrenner's social ecology theory emphasize that one member of the family does not act in isolation from other family members. Thus, individual family member characteristics, such as a child's disability, can have both positive and negative impact upon other members of the family. In this study, I critically examined the impact of the child's disability status, upon the family system. I addressed issues of family interaction by

asking questions relative to the impact of the child's disability upon the relationships in each of the four family subsystems: marital, parental, sibling, and extended family. I further explored the influence of family interactions by asking questions relative to the mothers' adaptability as demonstrated by utilizing coping strategies and accessing support system. An important aspect of my study was participants' perceptions of their young child relative to family functions; specifically how social, religious, economic, core-taking, and recreational activities impacted, or were impacted by, the child's disability.

I also analyzed participants' perceptions of positive experiences resulting from the child's disability. My study examined the impact of change on families as they moved through aspects of the early childhood life cycle. I gave detailed attention to the time of the child's diagnosis of disability, specific occasions engendering stress, and anticipated transitions, including the child's transition from early intervention into preschool services. Figure 2.3 illustrates how I developed interview questions based on the four aspects of the family systems framework. Aspects of Bronfenbrenner's social ecology theory also served as a basis for the development of questions for my study. Figure 2.4 represents my study's grounding in aspects of Bronfenbrenner's theory.

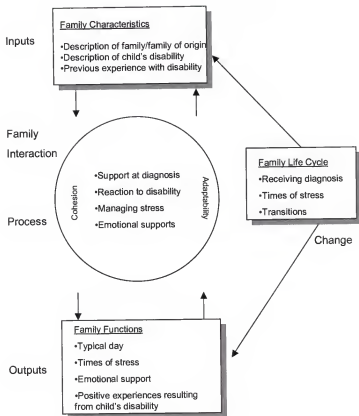


Figure 2.3 Inquiry Focuses Specific to Family Systems Framework

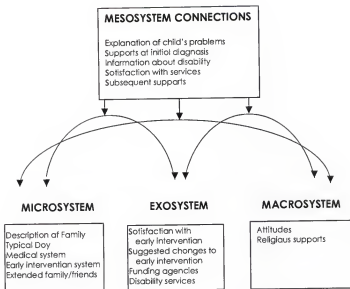


Figure 2.4 Inquiry Focuses Specific to Social Ecology Theory

I addressed mothers' microsystem components through eliciting descriptions of family characteristics, the progression of a typical day, and influences of medical, childcare, and early intervention systems. I also explored reactions of extended family members and friends and the supports they provided to the participants in order to address microsystemic components.

Several of my interview questions addressed aspects of the mesosystemic connections between mothers and medical and early

intervention service providers. These questions centered upon the quality of *interactions*. I asked mothers to describe the explanations of the child's diagnosis, supports at the time of initial diagnosis, provision of information regarding the child's specific disability label, satisfaction with early intervention services, and supports that were provided subsequent to the onset of services.

I examined exosystem influences by asking participants about their satisfaction with and desired changes in public policies governing the early intervention system, funding agencies, and overall disability services. I asked mothers about macrosystemic influences through questions regarding their perceptions of society's attitude toward individuals with disabilities and what role, if any, religion played in their efforts to cope.

Summary of Theoretical Foundation

When a family is faced with the disability of a young child, parents often find themselves subject to laws and policies of which they previously were unaware. Myriad medical and early intervention personnel now exert challenging influences on the family. Yet positive aspects, too, are to be expected as "many families describe lives that have been enriched and expanded through the experience of raising a child with a disability" (Cooley, 1994, p. 118). By examining Turnbull, Summers, and Bratherson's aspects of family characteristics, family interaction, family functions, and family life cycle within the overarching perspective of Bronfenbrenner's

social ecology theory, my study provides information about the direct influences of children with disabilities on their mothers' ability to come to terms with the disability.

Family systems theory holds that change in one part of the system affects other parts of the system and the system as a whole. Therefore, it is important to determine the effective ways in which professionals provide support for individual parental or family issues. Often when family supports are discussed it is only in the context of supporting the family in meeting early intervention goals. My study provides interventionists with additional understanding of mothers' coping strategies and the types of support that best contributed to 6 mothers' well being by examining their experiences as they parented young children with disabilities. Following is my review of the literature in three areas critical to families' experiences, (a) receiving the initial diagnosis, (b) coping strategies and support systems, and (c) parent-professional relationships.

Receiving the Initial Diagnosis

The time surrounding a child's initial diagnosis of disability can be very stressful for parents (Baxter, Cummins, & Pollock, 1995). Multiple aspects can contribute to this stress. In this section, I review research on (a) receiving diagnosis during the prenatal period, (b) type and severity of diagnosis, and (c) uncertain diagnoses.

Receiving the Diagnosis During the Prenatal Period

For some families, the diagnosis of disability occurs before the child is born. Congenital disorders such as microcephaly, spina bifida, Down syndrome, and other chromosomal defects can often be diagnosed through medical technology such as amniocentesis (Cohen, 1990, Rapp, 1998).

Concern for the way in which prenatal diagnoses are delivered has resulted in several studies (Elkins, Stovol, Wilroy, & Docas, 1997; Helm, Miranda, & Chedd, 1998; Stein, 1997). Elkins and his colleagues surveyed 101 mothers of a child with Down syndrome. Of these women, 40 had experienced at least one pregnancy after their child with Down syndrome. Out of the 40 women, 27 received genetic counseling and 20 had amniocentesis. Survey questions examined attitudes regarding amniocentesis, abortion, and prenatal genetic counseling techniques. These researchers found that expectant parents of prenatally diagnosed babies want to be provided with comprehensive information and more opportunities for counseling and support. Results of data on the social implications of parenting a child with Down syndrome gave an indication of the generally positive attitude of these mothers toward their children with Down syndrome. The participants' suggestions for physicians and genetic counselors included having broad discussions of both the positive and negative aspects of Down syndrome.

Helm et al. (1998) conducted in-depth interviews with 10 mothers of children who have Down syndrome. They examined the time between prenatal diagnosis of disability and the child's birth. Four mothers in this study reported that they "felt more positive when they were able to talk about realistic expectations for their babies with physicians and other clinicians who were well-informed" (p. 58). The mothers made suggestions for professionals conveying prenatal diagnoses of disability. The suggestions included (a) providing the diagnosis in person; (b) providing the news to both parents at the same time; (c) providing up-to-date printed materials; (d) accentuating the positives rather than the negatives or using negative terminology; and (e) recognizing the loss parents may feel, rather than pitying them.

Rapp (1998) summarized interviews she had conducted with families regarding prenatal diagnosis. Although no information was provided as to the type or rigor of these interviews, the author indicated that the research was conducted in New York City in the years 1984 - 1993. Rapp (1998) found that once a prenatal diagnosis was delivered, "religion provided orienting metaphors and beacons" (p. 63) for many women who cited their "faith in God" or their belief that abortion was "killing" as influencing their decision to continue with the pregnancy. The author indicated that religious backgrounds might influence parents to continue a pregnancy when chromosomal defects have been

determined, even when the parents may feel unequipped to raise a child with a significant disability. According to Rapp women turned to religion to sustain them in their decisions. They described their faith in God as well as support from the church family as assisting them in their decision to continue or terminate a pregnancy.

Rapp (1998) also found that ethnicity influenced parents decisions on prenatal testing. For example, she discovered reluctance on the part of some African American women to participate in prenatal testing because of a lack of trust in medical professionals. She indicated that, "Black communities have historically served as guinea pigs: the infamous Tuskegee syphilis experiment and the chaotic conditions attending early sickle-cell anemia carrier trait screening have both been widely reported in Black-focused media" (Rapp, 1998, p. 49). Rapp also found that Hasids and traditional Orthodox Jews might refuse offers of prenatal diagnosis because these families tend to screen potential spouses as carriers of Tay-Sacks disease before marriage. For some Hispanic families, language is a barrier making it difficult for parents to understand the significance of the testing. This lack of understanding may lead families to refuse testing. In addition to issues surrounding prenatal diagnosis, the level of stress families experienced varies with the type of severity of diagnosis.

Type and Severity of Disability

Not all families of children with disabilities experience stress to the same degree at the time of initial diagnosis. The nature of the child's disability may affect how individual families experience stress (Hanig & Winger, 1997; Rodrigue, Morgan, & Gefken, 1990; Scatt, Atkinson, Mintan, & Bowman, 1997; Singer & Farkas, 1989). For instance, several researchers documented increases in stress depending on the severity of the child's impairment (Hanig & Winger, 1997; Rodrigue et al., 1990; Singer & Farkas 1989). Hanig and Winger surveyed 65 families of young children with disabilities, including 22 families of infants or toddlers, using two self-report measures: the Questionnaire on Resources and Stress (Friedrich, Greenberg, & Crnic, 1983) and the Social Readjustment Scale (H Holmes & Rahe, 1974). They found that mothers of more severely impaired children reported increased stress.

Differences in levels of stress exist even when children are matched across differing diagnoses. Rodrigue and colleagues (1990) matched 20 mothers of children with autism with 20 mothers of children with Down syndrome by demographic variables and then matched these pairs with 20 mothers of developmentally normal children based on composite age equivalent scores from the Vineland Adaptive Behavior Scale (Sparrow, Balla, & Cicchetti, 1984). Families completed self-report questionnaires prior to a home visit. During the home visit, 20-minute videotapes were

mode during which the mothers were engaged with their child in interactive play. Parents' interactions with their children were then rated on a 9-point scale. Mothers' perceptions of low parenting competence, less marital satisfaction, and less family adaptability were prominent sources of stress for mothers of children with autism. Mothers of children both with autism and those with Down syndrome reported caretaker burden, family burden, and frequent use of self-blame as a coping strategy. Regardless of the diagnosis, as severity of the impairment increased, the stress for families also increased.

In some cases, the amount of stress parents experienced at diagnosis of disability was increased because the diagnosis was accompanied by the prognosis of limited life expectancy. For example, Quittner, Opiari, Regoli, and Jacobsen (1992) compared 20 mothers of infants and toddlers with cystic fibrosis with 20 matched controls. Using data generated through standardized questionnaires, these researchers determined that the stress mothers' experienced relative to caregiving activities was compounded by concerns for keeping the child alive. Thompson, Zenmon, Fonurik, and Sirotkin-Roses (1992) found similar stress levels in parents of 35 children age 4 to 14 with Duchenne muscular dystrophy. Evidence from self-report measures revealed that parental concerns regarding the life span of the child contributed to high levels of family conflict and poor adjustment to the child's diagnosis.

Recent research indicates that type of disability does not seem to affect the stress on the family. Cahill and Glidden (1996) examined the commonly held stereotype of children with Down syndrome having an easy temperament and agreeable personality, thus having less of a stressful impact on their family functioning than children with other disabilities. They found that previous studies supporting this premise might have been based on studies with sampling biases (Atkinson et al., 1995).

In their study, Cahill and Glidden used case-by-case matching of families raising children with Down syndrome with families whose children had other diagnoses. Included were children with cerebral palsy, autism, and seizure disorders. The families were matched on four variables, (a) child's level of functioning, (b) child age, (c) parental marital status, and (d) family income. Cahill and Glidden found no differences between matched groups on various measures of family functioning including family pride, family accord, marital satisfaction, and depression. These findings were replicated with multiple regression techniques. Based upon these findings, Cahill and Glidden posit that the type of disability does not alter stressors to the family. Not knowing the type of disability, however, seems to increase a family's stress level.

Uncertain Diagnosis

Not all disabilities are easily identified at birth. Additional concerns may arise when a young child's delay or disorder has nonspecific

features. The parents of these children often spend years searching for a diagnosis. As Morgan (1990) explains, "a major step in dealing with any problem is to be able to face it head on, obtain information about it and possibly locate other parents of children with similar problems for mutual emotional support" (p. 32). It is important for professionals to recognize the stress that parents may experience when there is no diagnostic label. Having a specific diagnosis permits parents to learn more about the future of their child or to find support from other parents with comparable experiences. More importantly, a specific diagnosis allows parents to come to terms with disability issues. Although the lack of a defining diagnosis is a concern for many parents, there does not appear to be a literature of empirical research examining this topic.

Concerns and Limitations of the Initial Diagnosis Literature

Although diagnosis of disability primarily occurs in the early childhood life stage, only three of the studies in the initial diagnosis literature had samples drawn exclusively from families where the child was an infant or toddler (Quittner, Oipari, Regali, & Jacobsen, 1992; Scott, Atkinson, Minton, & Bowman, 1997; Singer & Farkas, 1989). Each of these three studies relied on research methods with data collected through standardized questionnaires or surveys. However, there were statistical concerns regarding the small number of subjects in both the Scott et al. (1997) and Singer and Farkas (1989) studies. For instance, Scott et al.

resorted to pooling data from two different studies in order to increase the number of subjects and find significance in the results.

While some studies (Baxter, Cummins & Pallock, 1995; Rodrigue, Morgan, & Fefken, 1990) included qualitative methods of observation and interviews, in both of these studies the data was then rated and statistical procedures implemented. This procedure ignores the individual concerns that might be expressed by participants. Cahill & Glidden (1996) also employed qualitative interview methods, but only following the administration of three self-report questionnaires, which may have influenced participants' responses. In another study, (Helm, Miranda, & Chedd, 1998) interviews were conducted, but there was only selective transcription of interview data.

Two of the studies in the initial diagnosis literature (Baxter, Cummins, & Pallock, 1995; Scatt et al., 1997) were conducted in countries outside the United States. The children in these studies would not have received services through the federal Early Intervention Program. None of the reviewed studies in the initial diagnosis literature focused exclusively on the families of infants and toddlers and exclusively used qualitative research methodology.

Summary on Receiving the Initial Diagnosis

The literature on the initial diagnosis of disability indicates that families often experience stress whether there is a prenatal or postnatal

diagnosis. Yet research shows that mothers who had time to adjust to their child's disability before its birth generally had a positive attitude. This may also be because some mothers chose to continue a pregnancy after chromosomal defects had been identified because of their religious beliefs; consequently, their faith and religious community offered them additional support and encouragement. Unfortunately, some populations such as African Americans and Hispanics are less likely to engage in prenatal testing due to trust and communication barriers. The family experiences greater stress when a disability diagnosis is severe or life threatening. However, a difference in the type of disability—once thought to affect stressors—may not always cause variable effects. For those families who do not receive clear-cut diagnoses, the additional stressors can be present, yet there is no research or literature examining this situation. Families appear to experience stress differently and more qualitative research is needed to accurately reflect the complexity of these reactions. Likewise, the strategies a family uses to cope and their available supports may vary and affect how they deal with stress.

Coping and Supports

How parents respond to stressors may be dependent on their coping strategies and support networks. There is often an interaction between these because a parent's ability to cope with stress may be

mediated by supports. Conversely, accessing supports is acknowledged as a coping mechanism.

The variable potential for families to develop coping strategies has led many researchers to investigate the strategies employed by parents of children with disabilities and the conditions under which they develop (Gavidia-Payne & Staneman, 1997; Hanline & Daley, 1992; Judge, 1998; Shapiro, 1989; Sloper & Turner, 1993b). In this section, I provide a definition and description of coping strategies. I then present information on family functioning, adaptation to disability, and ethnic variables. Finally, I discuss literature on support systems for families of children with disabilities.

Coping

According to Margalit, Raviv, and Ankanina (1992), coping strategies are those "cognitions and behaviors used by the individual in evaluating stressors and in initiating activities with the aim of decreasing their impact" (p. 202). My analysis of the coping strategy literature reveals that several types of coping strategies exist and that researchers use a variety of terms to describe coping strategies. In this study, I used the categories determined by Thompson et al. (1992) who narrowed coping strategies to two major categories: adaptive and palliative.

Adaptive coping strategies. Individuals use adaptive coping strategies in an attempt to change themselves or the sources of stress. A parent of a child with disabilities may make attempts to adapt to the

stress or alter the cause of the stress (Judge, 1998). For example, a parent may choose to examine the positive aspects of the child's disability rather than focus on pejorative situations. Researchers have identified adaptive forms of coping to include problem solving, seeking social support, and cognitive restructuring or reframing (e.g., Judge, 1998; Margalit et al., 1992; Thompson et al., 1992). Additional adaptive strategies involve seeking information, social support, and spiritual support. Adaptive coping strategies are shown to be the most effective in reducing stressors.

Margalit, Raviv, & Ankonina (1992) conducted an Israeli study of parents of children with disabilities. They examined 78 parental couples with a child with a disability who volunteered to participate in the study. Disability categories included learning disabilities, mental retardation, and emotional/behavioral disorders. The mean age of the children was 11.08 years. Each family was asked to refer another family of their acquaintance who was similar in aspects of socioeconomic status and the number and ages of children, except for the presence of a child with a disability. These families served as matched controls. Four survey instruments, translated from English to Hebrew, were administered individually to mothers and fathers in their homes. These researchers found that parents of children with disabilities use fewer adaptive coping strategies than parents of children without disabilities. These researchers acknowledge that no comparisons have been made between families

with children with disabilities in Israel and the United States. They indicate a need for further research focusing on cross-cultural differences.

In contrast, Judge (1998) examined the coping strategies of 69 parents of children with disabilities from birth to age 5 involved in early intervention programs serving children with disabilities or who were at risk of developing disabilities. All of these children were eligible for special education services based on the state's criterion for developmental delay. Participants in the study completed a set of self-report measures including the Ways of Coping questionnaire (Folkman & Lazarus, 1988) and the Family Hardiness index (McCubbin, McCubbin, & Thompson, 1991). Judge concluded that adoptive strategies accounted for 58% of the coping strategies employed by parents in her study. Included in these adoptive coping strategies were: (a) concentrating on what had to be done next, (b) increasing efforts to make things work, and (c) creating positive meaning by coming out of the experience better. She concluded that coping strategies resulting in emotional and informational support tended to be predictive of a family's strength. As Judge (1998) explains, "This positive relationship between social support and family strengths reflects a family's preference to utilize resources both internal and external to the family" (p. 266). Although Judge identifies limitations to the study, including the exclusive use of self-report questionnaires and a limited number of participants, the use of adoptive coping skills is clearly

significant for these families. The fact that more than half of the coping strategies in Judge's study were adaptive is good because they are more effective than palliative strategies.

Palliative coping strategies. At times parents may use less effective coping strategies referred to as palliative coping strategies (Atkinsan et al., 1995; Margalit & Ankanina, 1991; Margalit, Raviv, & Ankanina, 1992; Staper & Turner, 1993a). These strategies are emotion-focused and include avoidance, minimizing, denial, self-blame, distancing, and wishful thinking. For example, a parent of a child with a chromosomal disability may expend time and energy in self-blame due to the etiology of the child's disorder. Palliative coping strategies may result in a temporary reduction of stress, but do not increase the parent's ability to cope with ongoing stressors. They may, however, allow parents to buy time until they are in a position to utilize the more successful adaptive coping strategies. As Judge states

Blaming oneself, believing the problem will go away, engaging in activities that prevent confronting an issue, and trying to keep one's feelings from others are all evidence of passive appraisal [palliative coping]. Passively reacting to a problem may delay a family's active or immediate response, and the use of these coping strategies . . . negatively impact a family's sense of mastery or competence. (p. 266)

Margalit and Ankonina (1991) examined 71 Israeli couples with a child with a disability matched on parental ages and education level with 77 couples whose children did not have a disability. Participants

completed Hebrew adaptations of four questionnaires; the Affect scale and the Coping scale of the Revised Health and Daily Living (Moos, Cronkite, Billings, & Finney, 1987), the Family Environmental scale (Moos & Moos, 1983), and the Child Behavior checklist (Achenbach, 1979; Achenbach & Edelbrock, 1983). A one-way multivariate analysis of covariance (MANCOVA) was performed. These researchers found that parents of children with disabilities report higher negative (distressed) affects and adopt more avoidant (palliative) coping skills representative of efforts to deny, minimize, or escape from the stress of parenting a child with a disability. They caution, however, that the factors studied accounted for only part of the variance between the families of children with and without disabilities and suggested the need for "detailed research defining possible additional predictors of healthy and maladaptive functioning, clarifying their mediating role with respect to stress" (p. 297).

Sloper and Turner (1993b) conducted a British study examining the adaptation to disability in 107 parents of children between 6 months and 13 years with severe physical disabilities. Infants and toddlers made up 34 percent of the subjects' children. Fathers and mothers were asked to independently complete a packet of self-report questionnaires including the Moloise Inventory (Rutter, Tizard, & Whitmore, 1979), the Judson Self-Rating scale (Judson & Burden, 1980), and the Ways of Coping

questionnaire (Revised) (Folkman & Lazarus, 1985). In addition, 105 mothers were interviewed in their homes following completion of the survey instruments.

Univariate analysis between the descriptor variables of child characteristics, life events, parental resources, and coping strategies as well as the outcome measures of psychological distress, satisfaction with life, and adaptation to the child was conducted for both mothers and fathers. High use of the palliative strategy of wishful thinking was related to poorer parental satisfaction with life and adaptation to the child.

This study utilized mixed methods including both survey research and qualitative interviews. However, only one direct quotation from a participant was provided in reporting the results. Rather, researchers rated interview data and applied statistical analysis. The researchers also acknowledged that they could not assume causal links between descriptor and outcome variables from a cross-sectional study.

Atkinson et al. (1995) also used mixed methods in their study of 56 Canadian mothers of toddlers with Down syndrome. They addressed the influence of coping on the maternal sensitivity of the mothers to their toddler's. Maternal sensitivity is defined as "the accurate perception, interpretation, and response to a child's signals" (Atkinson et al., 1995, p. 669).

Self-report measures used in this study included the Approach-Avoidance scale (Rath & Cohen, Roth, 1986), Miller Behavioral Style scale, (Miller, 1980), and the Profile of Mood States (McNair, Larr, & Doppleman, 1971). The mothers were also videotaped in their homes while (a) feeding their children and (b) completing the packet of self-report measures or responding to an interview in their children's presence. Researchers designed this activity to "exert minor stress on mother-child relations by obliging mother to balance the requests of the interviewer with those of her child" (Atkinson et al., 1995, p. 670). The videotaping was repeated in several different locations and contexts over a 2-year period, resulting in six total occasions. Three observers independently rated maternal sensitivity during videotaped sessions. Interobserver reliability was .97. Although observations were made of the mother-child interactions, there was no qualitative analysis. Reported results from the study indicated that mothers who display avoidance, a palliative coping strategy, might display reduced sensitivity toward their children.

Summary of coping. The literature indicates that two types of coping, adaptive and palliative, can assist families in mediating the stress associated with parenting a young child with a disability. Although both adaptive and palliative coping strategies can serve to reduce stress, adaptive strategies are identified as most successful in reducing long-term stressors. The coping strategies employed by families of young children

with disabilities can be important predictors of family functioning and adaptation to disability.

Family functioning and adapting. Research examining family functioning for parents with young children in an early intervention program revealed that mothers and fathers tend to use different adaptive coping techniques. Studies show that a family's ability to cope effectively with disability relies on various factors such as communication, cohesion, and outside support, and that, vice versa, an effective use of adaptive coping techniques indicates a family with strong communication, cohesion, and outside support. The times when these coping techniques are relied upon most are during the initial diagnosis and when the child enters school. An analysis of these techniques across ethnic variables show adaptive coping strategy use varied along ethnic lines.

Gavidia-Payne and Staneman (1997) addressed the relationship among parents' coping strategies and family functioning in a study of 80 two-parent families of 1-year-old to 5-year-old children participating in an early intervention program. Twenty-six percent of the subjects were parents of infants and toddlers. Participants completed questionnaires distributed through their children's special education agencies. Measures included the Family Support scale (Dunst, Trivette, & Deal, 1988), Dyadic Adjustment scale (Spanier, 1976), McMaster Family Assessment device (Miller, Bishop, Epstein, & Keitner, 1985) Hassels and Uplists scale (DeLangis,

Falkman, & Lazarus, 1988) and Center for Epidemiologic Studies Depression scale (Radloff, 1977). These researchers found that the ability of the family to cope was influenced by family functioning and parental involvement in the child's early intervention program. There was, however, differentiation between the types of coping strategies used by mothers and fathers. Mothers were reported to use adaptive problem-focused strategies. Of particular note were the actions mothers initiated, taking an active role in their children's intervention programs including involvement in therapy sessions and consultation with interventionists. These researchers also found that mothers' interpretations of their family's functioning indirectly affected their involvement, because "mothers' perceptions of their family interactions as being more healthy enhance their coping abilities, which in turn mobilize their involvement" (p. 713). Healthy family relationships strengthened mothers' capacity to use a wider range of coping strategies, including both problem-focused and spiritual orientations.

Gavidia-Payne and Stoneman (1997) also found that coping abilities influenced fathers' involvement in their children's intervention programs. Although fathers' participation is generally more indirect than that of mothers, the adaptive coping strategies they employed, seeking information and social supports, as well as coping by turning to religion, were predictors of their level of involvement in the child's program. These

researchers discovered that fathers became involved by seeking services for their children, even though they may not have attended meetings or actively communicated with service providers.

Dyson (1996) examined the experience of families of children ages 7 - 14 with learning disabilities relative to parental stress, family functioning, and sibling self-concept. Nineteen families, each with one child with and another without learning disabilities, were questioned using the questionnaire on Resources and Stress-Short Form (Friedrich, Greenberg, & Crnic, 1983), The Family Environment scale (Maas & Moos, 1981) and The Piers-Harris Children's Self-Concept scale (Piers, 1984). In addition, the families were asked two open-ended questions relative to their family functioning. These questions were analyzed using the constant comparison method by two independent coders. The results of this study found that the functioning of families and the self-concept of siblings was comparable to that in families of children without disabilities, but the parents did experience greater stress than that of parents of children without disabilities. Methodological concerns arise, however, as there was no comparison group in the sample. These authors made no report of specific strategies used by these families to lessen stress.

Holland (1996) suggested a family's ability to cope effectively with disability related stress is dependent on a variety of factors. These factors include open, honest communication, a high level of emotional

expressiveness within the family, family cohesion and stability, and social-emotional support. These factors are significant regardless of the child's age or disability diagnosis.

Judge (1998) examined the relationship between the use of coping strategies and the family's sense of mastery or competence using two self-report measures: the Ways of Coping questionnaire (Folkman & Lazarus, 1988) and the Family Hardiness scale (McCubbin, McCubbin, Thompson, 1991). The Family Hardiness scale measures perceptions of internal family strengths and durability such as (a) control over life events and hardships, (b) change as beneficial and growth producing, and (c) active orientation in managing stressful situations. Sixty-nine parents of children with disabilities ranging in age from birth to age 5 participated in the study. Judge found that adaptive coping strategies such as seeking social support and information were predictive of family strengths. She cautions, however, that the "exclusive use of self-report questionnaires completed by parents and the limited number of participants may limit the findings" (Judge, 1998, p. 266). Adaptive coping strategies are especially relied upon at the time of initial diagnosis and when the child enters school.

Sloper and Turner (1993b) investigated the association between coping strategies and adaptation to the child in an examination of mothers and fathers of 107 children with severe physical disabilities. They

defined severe motor disability as the likelihood that the child would be unable to walk more than a few steps independently. These researchers studied families confronting two critical times in the life cycle, the initial diagnosis of disability and when the child enters school. Coping strategies were measured using the Ways of Coping questionnaire (Revised) (Folkman & Lazarus, 1988) with adaptations from Knussen, Sloper, Cunningham, & Turner (1992). Parents' adaptation to the child was measured using the Judson Self-Rating scale (Judson & Burden, 1980).

Two adaptive coping strategies, problem solving and seeking support, were found to have significant correlation with parents' adaptation to their child. Coping by seeking support was particularly significant at the time of initial diagnosis. Although problem solving was found to be significant for both mothers and fathers, the statistical significance was stronger for fathers than for mothers.

Shapiro (1989) investigated the coping strategies employed by mothers of young children with developmentally delayed children between the ages of 1 and 5 years who participated in a support group. She used three inventories: The Center for Epidemiological Studies Depression scale (Roberts, 1980), The Coping with Stress inventory (Billings & Moos, 1981), and a questionnaire on Resources and Stress (Holroyd, 1974) along with individual in-depth semi-structured interviews. Shapiro found that parental stress was reduced as parents (a) received support

from others and (b) gained more understanding and acceptance of their child's disability. While I've presented these findings as universal, ethnic variables should be considered as well.

Although caution is advised regarding generalization of ethnic characteristics, an awareness of the different use of coping strategies across ethnic groups is important for interventionists concerned with parents' adaptation to their child's disability. Hanline and Daley (1992) investigated the relationship between maternal perceptions of family coping strategies and strengths in 59 Hispanic, 66 African-American, and 81 Caucasian families of infants and toddlers with disabilities. These researchers employed within-ethnicity analyses to provide a descriptive approach to understanding family coping strategies and strengths with additional comparisons of families of children with and without disabilities.

Hanline and Daley (1992) used two self-report measures, the Family Crisis Oriented Personal Evaluation scales (F-COPES) and the Family Strengths questionnaire (Olsen et al., 1985). The F-COPES includes four scales that measure a family's adaptive coping abilities: (a) Acquiring Social Support (from friends, relatives, extended family, and neighbors); (b) Seeking Spiritual Support; (c) Mobilizing the Family (to acquire help from community resources); and (d) Reframing (events to make them more manageable). The Family Strengths questionnaire measures the family strengths of pride and accord. The Pride scale assesses perceptions

of respect, trust, and loyalty within the family, while the Accord scale measures the family's sense of mastery or competence.

Hanline and Daley (1992) found that Hispanic families of children with disabilities have well-developed coping strategies. One strategy, reframing, was particularly helpful for these Hispanic families in maintaining family strengths as measured by the pride dimension (respect, trust, loyalty). African-American families both with and without children with disabilities also use the reframing coping strategy. Having a child with disabilities did not appear to affect either family accord or family pride for African American families.

Hanline and Daley (1992) point out that Caucasian families of children with disabilities use the adaptive coping strategies of acquiring social support, seeking spiritual support, and mobilizing the family to acquire help from community resources at a much greater degree than did Caucasian families of children without disabilities. They argue, however, that even with the use of these coping strategies, the presence of a child with disabilities detrimentally influenced perceived family strengths as Caucasian mothers reported less family pride and less accord.

A limitation of this study centers on sampling concerns. There was no random sampling of participants as all were recruited from early intervention and childcare programs. Additionally, results may be limited since only self-report measures were used in the study.

Summary of coping. The literature reveals the different coping styles of parents of young children with disabilities based on gender and ethnic variables. Mothers were generally more involved in the child's therapy and intervention sessions, while fathers participated more indirectly by seeking out information and social supports. Both mothers and fathers often turned to religion. In general, Hispanic and African American families predominantly relied on the strategy of reframing, while Caucasian families focused more energy on seeking social support. While one should be careful not to generalize too much across gender and ethnic lines, increasing service providers' awareness of the different coping styles can help them facilitate parents' adaptation to their child's disabilities, especially at the stressful times of initial diagnosis and when the child starts school. Interventionists, as well as other parents of children with disabilities and religious communities, combine to create an effective support system, which increases parents' ability to cope.

Supports

Available supports are perhaps one of the most important factors affecting how families of a child with a disability experience stress. Cooley (1994) proposed that a "community-based, family-centered system of family support includes three subsystems" (p. 118). Included in Cooley's description are (a) natural supports, including spouses, extended family members, friends and neighbors, churches, and other community-based

systems; (b) *informal supports*, including contact with parents of children with disabilities through chance meetings, informal networking or more formal parent-to-parent programs; and (c) *formal supports* including ways to assist the family in meeting its daily needs and the medical and educational needs of the child, such as financial and health insurance benefits, service coordination, respite care, early intervention programs, and other state-supported resources.

Natural supports. Cooley (1994) described natural supports as spouses, extended family members, friends and neighbors, churches, and other community-based systems. Spouses and family members may assist by providing transportation to therapy sessions or by caring for siblings, thus allowing primary caregivers time for other tasks specific to the child with a disability. Often friends and neighbors, churches, and other community-based systems provide a sounding board for family members about concerns relative to their child with a disability.

Baxter, Cummins, and Pollock (1995) conducted a seven-year longitudinal study of Australian parents of children with a diagnosis of intellectual disability. At the time of initial investigation, 132 parents participated in the study. Of these, 60 had children between ages 3 and 5, 35 had children between ages 10 and 12, and 37 had children between ages 17 and 19. Participants were asked to rate stress attributed to the child with a disability on a 3-point scale. These responses were

compared to parent evaluation on the same 3-point scale of stress attributed to the youngest child in the family without a disability. These researchers then conducted a retrospective evaluation of parental stress experienced in three life events: (a) initial diagnosis, (b) child's entry to school, and (c) child leaving school. Parents were also questioned about support in relation to the same three life events through the open-ended question, "What helped most in coping at the time?"

These researchers found that natural supports were employed most often following the initial diagnosis. Spouses, parents, and other members of the extended family network as well as close friends were all included in respondent's consideration of who had helped them to cope at this time. Fathers also indicated receiving support in their work environment. These results are supported in the findings of Helm, Mirondo, and Chedd (1998) in their investigation of mothers' need for supports from the time of prenatal diagnosis of Down syndrome to the birth of the child. The importance of support from family members and friends was a general theme mentioned by most of the ten mothers interviewed in the Helm et al. study. Though natural supports continue to be important, as the child reaches school age parents may reach out further.

Informal supports. Cooley indicated that informal supports consist of contact with other parents of children through chance meetings, informal networking or more structured parent-to-parent programs.

Boxter, Cummins, and Pollock (1995) noted that contact with other parents was found to help the coping process of the time children first started school. Koroloff and Friesen (1991) conducted a study of over 800 parents of children between birth and age 21 with emotional disorders. They made comparisons between parents who were members of support groups and those who were not. These researchers found that participants who were members of support groups valued talking with other parents experiencing similar disability-related activities. Often these activities resulted in the sharing of additional information about a child's disability or available services. Judge (1998) also advocated the use of support groups to provide emotional support for parents of children with disabilities.

In a study of attitudes of parents toward support groups, Smith, Gorbard, Dale and Drucker (1994) found their participants held two aspects to be important: (a) the support parents received from the group and (b) the information they received about resources and their child's disabilities. In contrast to the Boxter et al. study, which found support groups become helpful as children moved into school-based settings, Smith and colleagues' participants reported that parent support groups were most helpful at the time of diagnosis and at time of family crisis. In both studies, however, the participants valued parent-to-parent contact.

Yet parents' need for support extends beyond sharing experiences and information.

Formal supports. Cooley delineated formal supports as consisting of ways to assist the family in meeting its daily needs and the medical and educational needs of the child. Included in formal supports are financial and health insurance benefits, service coordination, respite care, early intervention programs, and other state-supported or agency resources. Researchers dispute the significance of formal supports to reduce stress levels experienced by families of a child with a disability (cf. Scott et al., 1997; Beckman, 1991).

Scott, Atkinson, Minton, and Bowman (1997) conducted a study that compared the distress level of Canadian parents who had infants with Down syndrome to that of control parents of infants who were normally developing. The initial survey involved 88 participants and 58 control parents. A replication involved 100 study parents with 70 control parents. Participants were administered the Beck Depression inventory (Beck, Rush, Shaw, & Emery, 1979), the Intrusion subscale from the Impacts of Events scale (Horowitz, Wilner, & Alvarez, 1979) and the Profile of Mood States (McNair, Lorr, & Doppleman, 1971). Although parents who had children with Down syndrome showed greater depression than the comparison group, effect sizes were small. For example, the prevalence of clinical depression was 5.56% for participants and 4.26% for control

parents. These researchers pooled the data from the initial and the replication study in order to increase the number of participants sufficient to find significance. However, Scott et al. concluded that parenting an infant with Down syndrome may cause less distress than previously thought and attributed this to the fact that all parents were receiving services from developmental disability agencies where professional counseling and supports were available. It should be noted, however, that these researchers were only looking for evidence of clinical depression. There was no measure for the more transient situational depression that may exist as parents come to terms with parenting a child with Down syndrome.

In a similar study, Beckman (1991) compared 27 mothers and 27 fathers of children with disabilities to 27 mothers and 27 fathers of children without disabilities in respect to the amount of stress, caregiving requirements, and social support they experienced. Subjects were matched according to general demographic characteristics including parents' age, parents' education, number of siblings, ethnicity, social class, and average income. Parents were interviewed in the family home using the three self-report measures, the Parenting Stress index (Abidin, 1983), the Carolina Parent Support scale (Bristol, 1979), and the Caregiving questionnaire (Beckman, 1983). She found that parents of children with disabilities reported significantly more stress than parents of children

without disabilities. Beckman found that for mothers, formal support was not significantly associated with lower stress levels. However, formal support assisted fathers in mediating general life stress. Beckman suggests that different or additional sources of support may facilitate coping for fathers.

Honig and Winger (1997) investigated the relationship between maternal stress and professional supports. They used the questionnaire on Resources and Stress (Friedrich, Greenberg, & Crnic, 1983), the Social Readjustment rating scale (Holmes & Rahe, 1974) and individual interviews to collect data from mothers of 65 children between birth and age 6 with disabilities. The authors highlighted several important findings, including (a) mothers who perceived the child's degree of physical incapacity as more severe may find their needs for respite care more urgent; (b) agency supports are effective as a buffer against increased maternal stress regardless of the extent of individual maternal support networks; and (c) the greater the proportion of the child's life for which the mothers had received professional support services, the less pessimistic they were about the child's future.

An interesting finding from this study was that married mothers in this study reported higher stress levels than single mothers. The authors suggested that additional professional and agency services may help alleviate this increased stress by reaching out more to fathers of children

with disabilities. Fathers also need opportunities to express concerns and negative feelings (Herbert & Corpenner, 1994; Hornby, 1992). Professionals can assist fathers in developing communication and coping skills that will minimize stress within the family. Professionals can also provide practical ideas for fathers so that they can emotionally support the mothers, who most often bear the major burdens of caring for a young child with a disability (Quittner, Opiropi, Regoli, & Jacobsen, 1992).

Summary of supports. Support systems—including natural, informal, and formal supports—help parents cope effectively which facilitates family functioning and adaptation to disability. Natural supports such as spouses and extended family are generally relied upon immediately following the initial diagnosis. In one study parents indicated that other parents and support groups were most helpful at the time of diagnosis and family crises, but other studies reported that parents tended to enlist these informal support systems when children first started school. In all studies, parent-to-parent contact was highly valued. In one study, fathers appeared to receive more relief from stress due to formal supports, such as state programs and financial benefits, than mothers, yet other studies reported that mothers who had received professional services for a longer time felt more optimistic about their child's future. An interesting discovery of one study was that single mothers reported lower stress levels than married mothers, indicating that maternal stress may be aggravated by a

wife's need to help her husband come to terms with the situation or by his denial of the reality of the disability. Whatever the cause, service providers can help alleviate this stress by reaching out to fathers and helping them develop communication and coping skills so that they do not become additional burdens for the mothers but function as natural supports.

Concerns and Limitations of the Coping and Support Literature

A number of studies have been conducted that examine the relationship between support and coping strategies. However, this literature has been conducted primarily on older children. Of the 16 investigations examined under this category, only three studies were conducted exclusively with parents of infants and toddlers (Atkinson et al., 1995; Hanline & Daley, 1992; Scott, Atkinson, Minton, & Bowman, 1997). Of these three studies, only one (Hanline & Daley, 1992) was conducted in the United States. This study relied on quantitative methodology and reported statistical limitations due to the limited number of participants. Five studies in this category use qualitative research methodology. However, four of the five studies were conducted outside the United States, precluding enrollment of children under the federal Individuals with Disabilities Education Act (IDEA). The fifth qualitative study employed selective transcription of interview data (Helm et al., 1998). None of the studies reviewed examining coping and support systems focused

exclusively on families of infants and toddlers with disabilities and relied solely on qualitative methodology.

Summary of the Coping and Supports Literature

A parent's use of effective coping strategies and helpful support systems is important in response to family stressors. Effective coping can facilitate family functioning and adaptation to disability. The interaction between these coping strategies and available supports is important for both parents and interventionists. Although there may be ethnic variables in the way families cope and access supports, professionals are cautioned against making generalizations regarding families' capacity to cope based upon ethnicity. It is important for professionals to foster parent-professional relationships by recognizing and encouraging family coping strategies and support systems.

Parent-Professional Relationships

Judge (1998) asserts that professional interactions with families can serve to either empower families or usurp families' control. Therefore, the manner in which the diagnosis is delivered, the perceived concern from professionals, and the amount of information that is offered to families may influence how families approach future interactions with other interventionists (Sloper & Turner, 1993b). In this section, I discuss the literature on parent-professional interactions at initial diagnosis of disability

followed by a discussion on the manner in which services are provided during subsequent parent-professional relationships.

Parent-Professional Interactions at Initial Diagnosis

Sloper & Turner (1993a) suggest that parental satisfaction with the disclosure of disability may depend on two variables: (a) the disclosure process and, (b) parent and child characteristics. They conducted a study of 107 British families of children with severe physical disabilities including cerebral palsy, spina bifida, and muscular dystrophy. Children ranged between 6 months and 13 years. They collected satisfaction data through interviews with the mothers. They asked mothers to rate their satisfaction with the way the news of the child's disability was disclosed to them based upon a 5-point scale. In addition, both mothers and fathers completed self-report questionnaires including parental demographic variables, child disability variables, the Eysenck Personality inventory (Eysenck & Eysenck, 1964), Ways of Coping questionnaire (Revised) (Folkman & Lazarus, 1985), and the Marlow-Crowne Social Desirability scale (Stratham & Gerbasl, 1972).

These researchers found maternal satisfaction with the disclosure experience to be only 37 percent. The relationship between the parental satisfaction with disclosure and disclosure variables, child variables, and parental variables was examined using multivariate analyses. Three variables, (a) characteristics of the person delivering the diagnosis, e.g.,

whether he or she had "a sympathetic, understanding, and approachable manner" (Slaper & Turner, 1993a, p. 823); (b) provision of adequate information with opportunities to ask questions; and (c) manual social-class backgrounds of the parents were each determined to have a significant relationship to the mothers' satisfaction ratings.

Quine and Rutter (1994) examined parental satisfaction of physician-parent communication during initial diagnosis of disability. They based questionnaire items on two predominant models of doctor-patient communication. One model, conceived by Ley (1988), examined the communication interaction from a cognitive standpoint. Quine and Rutter integrated factors from this model into their questionnaire. The factors were (a) the amount of information given, (b) the parent's understanding of the information, (c) the technical nature of the information, and (d) the parent's ability to remember the information provided.

Karsch, Gazzi, and Francis (1968) developed another model. This model focused on affect and social interaction during doctor-patient interactions. Based upon this model, Quine and Rutter examined five additional factors. The factors were whether (a) the doctor was direct, (b) the doctor was approachable, (c) the doctor understood the parent's concern, (d) the doctor was a good communicator, and (e) the doctor was sympathetic.

Quine and Rutter surveyed 166 British mothers of children up to 16 years of age with severe learning disabilities. They asked several questions regarding satisfaction with the communication process during initial diagnosis of the disability. The mothers' satisfaction was rated using a 5-point scale. In analyzing the data, these researchers found that the most important predictor of parental satisfaction with the communication process was the doctor's effective behavior. They found three main components led to satisfaction in the way news of a child's impairment are given. The first was that parents wanted to know as soon as possible if something was wrong with their child. This was true even if the doctor was unsure of the exact nature of the impairment. Second, the parents wanted to feel that the person who communicated the information was sympathetic to their situation. The third component was the importance of receiving adequate information about their child's condition. How a doctor delivers news of an initial diagnosis is a parents' first concern. Soon, however, the parent begins evaluating how all types of services are provided.

Manner in which Services are Provided

How services are provided may also affect families' views of professionals' helpfulness. Judge (1998) suggested utilizing a family's own social support network in a collaborative manner with professional services. She found a positive relationship between social support and

family strengths. Thus, a majority of families preferred to utilize resources both internal and external to the family. Judge recommended that professionals assist families in developing a network of individuals who could provide emotional support and information.

Turnbull and Turnbull (2001) referred to collaboration as "the dynamic process of families and professionals equally sharing their resources in order to make decisions jointly" (p. 50). Cooley supported this position by stating, "professionals who foster cooperative partnerships with families are informally enhancing a family's self-confidence and feelings of mastery and control" (p. 118). Professionals can be helpful in assisting families to recognize positive supports and coping strategies. Then, as families make choices whether to pursue or reject supports, professionals continue to support families in their decisions.

Concerns and Limitations of the Parent-Professional Relationship Literature

The literature directly studying parent-professional relationships appears to be limited. Although some studies on support systems touch on the desired characteristics of professionals as part of the formal support system (i.e., Baxter et al., 1995; Judge, 1998), only two studies (Quine & Rutter, 1994; Sloper & Turner, 1993a) provided empirical evidence of parental satisfaction with the interaction. Both of these studies were conducted outside of the United States and involved families with older children and relied on quantitative research methodology. Although the

Sloper and Turner (1993a) study included interviews with mothers, they rated and quantified their data rather than reporting the individual voices of participants. No studies examining parent-professional relationships were found that relied exclusively on qualitative research methodology while focusing only on the families of infants and toddlers.

Summary of Parent-Professional Relationships

Both initial interactions between families and professionals and the manner in which subsequent services are provided may influence a family's later satisfaction with early intervention. Parents showed the greatest satisfaction with doctors who communicated their concerns immediately, showed sympathy, and provided adequate information regarding the child's condition. Researchers recommended that service providers work collaboratively with a family's own support network—even assist families in developing a support network—in order to empower families and build a more positive parent-professional relationship. No matter what support systems and coping strategies families do or do not choose to implement, however, professionals should support families in their decisions.

Problem

The Individuals with Disabilities Education Act (IDEA) specifies the provision of family-centered practices to encourage involvement of families of infants and toddlers with disabilities in their children's

intervention programs. Professionals can support family participation by understanding how to assist families in coping with the stresses that having a child with a disability may present. Professionals providing initial diagnoses of disability to families must recognize that the situation may be influenced by the manner in which the diagnosis is delivered.

Turnbull and Turnbull (2001) suggest that service providers can provide support by assisting families in cultivating the use of coping strategies. The coping and support literature lends evidence to the importance of learning effective coping strategies to lessen the negative effects of stressors that may accompany parenting a child with a disability. Interventionists are in an ideal position to provide training to families in effective coping procedures. Professionals can also facilitate support networks for families, linking them with other families of children with disabilities, agency personnel, and community support systems.

The literature I reviewed substantiates the importance of examining the issues facing mothers of infants and toddlers with disabilities as they face the early adaptation to the child's disability. However, the majority of the research literature relative to initial diagnosis, coping strategies, and supports for families was conducted with families of older children exclusively using questionnaires or survey instruments. While these instruments may report parents' perceptions of these issues, the participants' responses are limited to those aspects included in the rating

scales. This methodology can not provide a full picture of what parents perceive as important relative to the initial diagnosis, coping strategies and supports, and parent-professional relationships.

What the literature fails to address are the personal and individual aspects confronting mothers, particularly those who live in the United States, during the first three years of a child's life following a diagnosis of disability. Attempts to understand what issues are important to these mothers may best be determined by allowing them to report their own perceptions of the reality of living with disability. Thus, the use of qualitative methodology is essential in addressing these issues. In this study, I employed qualitative methodology in order to obtain mothers' perceptions of living with an infant or toddler with a disability. The goal of my interviews and observations was to find out how 6 mothers learned about, came to understand, and responded to the evolving reality of their children's disabilities. The research was guided by five research questions:

1. How did these mothers respond to the initial disability diagnosis?
2. What did mothers perceive to be the long- and short-term implications of the diagnosis for their child, their families, and themselves?
3. What types of support did mothers seek, find, and receive for their child, their families, and/or themselves?
4. What qualities did mothers value in professionals?
5. What changes did mothers suggest to early intervention services?

In the following chapter, I discuss my qualitative research methods in-depth and explain why and how I focused on the mothers' perceptions of their experiences caring for a child with disabilities from birth through age 2.

CHAPTER THREE METHOD

Introduction

In this chapter, I present the research perspective and parameters of my study. Included are descriptions of the research setting, study participants, data collection, data analysis, and trustworthiness. In conducting this study, I was interested in the mothers' perceptions as they parent children birth through age 2 with disabilities. Qualitative methodology including ethnographic interviews, participant observation, and document analysis was most appropriate for my study because of my interest in each mother's specific thoughts and feelings as she coped with her child's initial disability diagnosis and worked to access intervention services.

The Qualitative Research Paradigm

Qualitative research methodology is supported by the interpretivist, or constructivist, paradigm. As Glesne (1999) explains

Interpretivists assume that they deal with multiple, socially constructed realities or "qualities" that are complex and indivisible into discrete variables, they regard their research task as coming to understand and interpret how the various participants in a social setting construct the world around them. (p. 5)

According to this paradigm, an individual's perceptions are shaped by their experiences and values (Sherman & Webb, 1997). I asked 6 mothers about parenting children with disabilities and learned the process they encountered in coping, accessing services, and coming to terms with their children's disabilities. The goal of ethnographic research is to understand the meanings of actions and events from the perspective of the persons experiencing them (Spradley, 1979, p. 5). My objective was to report the experiences of participants in enough breadth and depth to allow others to understand them, (Shimahoro, 1997). As Spradley describes

The essential core of ethnography is this concern with the meaning of actions and events to the people we seek to understand. Some of these meanings are directly expressed in language; many are taken for granted and communicated only indirectly through word and action. But in every society people make constant use of these complex meaning systems to organize their behavior, to understand themselves and others, and to make sense out of the world in which they live. (p. 5)

Because the purpose of my study was to understand how mothers of infants and toddlers with disabilities think, feel, and act while coping with an initial diagnosis of disability and while accessing intervention services, ethnographic methods, including interviews, observations, and artifact analysis were employed for this study.

Qualitative researchers enter their investigations without pre-established answers to issues, problems, and/or research questions (Sherman & Webb, 1997; Spradley 1979; Strauss & Corbin, 1998). As

Sherman and Webb (1997) explain, "The aim of qualitative research is not verification of a predetermined idea, but discovery [emphasis in original] that leads to new insights" (p. 5). This is not to say that I approached this study without direction. Based upon established family interaction theories, professional experience, and current literature, I developed five "foreshadowed" questions to guide the study:

1. How did these mothers respond to the initial disability diagnosis?
2. What did mothers perceive to be the long- and short-term implications of the diagnosis for their child, their families, and themselves?
3. What types of support did mothers seek, find, and receive for their child, their families, and/or themselves?
4. What qualities did mothers value in professionals?
5. What changes did mothers suggest to early intervention services?

Next, I chose methods best able to help me achieve answers to my research questions. The following sections clarify my choices of research setting, participants, data collection and analysis, and the overall trustworthiness of the study.

Parameters of the Study

Setting

I conducted the study in a mid-sized rural area of Florida. I interviewed mothers in their homes and observed them both in their

homes and in offices where therapists delivered services to their children with disabilities. I interviewed service providers in their work settings.

Participants

The participants in this study were 6 mothers of young children with disabilities. Figure 3.1 displays the interview schedule for the 6 participants. Each participant met the exclusionary criteria of being a mother of a young child, birth through age 2, who was receiving early intervention services under the auspices of the state of Florida's Part C early intervention program. Four of the participants participated in a pilot study conducted from January to April 2000. I enlisted 2 additional participants from the same program for the current study August 2000 through August 2001. To maintain confidentiality, the Family Resource Specialist at the early intervention program or the Director of Early Intervention services at a local early intervention center made initial contact with all mothers regarding the study. Once mothers indicated they would participate, I contacted them and provided additional information about the study.

For the purpose of confidentiality, the mothers who participated in this study are referred to as Jani, Rani, Tami, Lori, Suni, and Boni. Table 3.1 details participants' demographic information. Jani and Rani's families were no longer participating in the early intervention program past the point of the pilot study because their children had turned 3 years of age.

However, the data collected from these mothers through semi-structured interviews during the pilot study were relevant to the research questions of this study and were included in analysis. Tami and Lori also previously

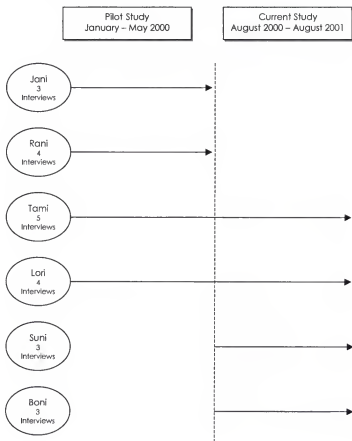


Figure 3.1 Interview Schedule

Table 3.1
Participant Demographics

Name	Joni	Rani	Tami	Lori	Suni	Boni
Age	38	37	33	24	34	33
Employment	Nurse	Medical transcriptionist	Nurse	Apartment Manager, student	Stay-at-home mother, previous recreation therapist	Financial analyst
Education	Associate	Bachelor	Masters	Some college	Masters	Bachelor
Marital Status	Married	Married	Married	Married	Married	Married
Spouse Employment	Security Sergeant	Operations Manager	Computer Information Specialist	Security, Military Reserves	Banking, Chief Operations Officer	Engineer
Spouse's Education	Associate	Associate	Bachelors	Some College	Bachelors	Masters

Table 3.1. Continued

Name	Joni	Roni	Tami	Lori	Suni	Boni
Child's Name	Volerie	Steven	Daniel	Megon	April	Derek
Child's Diagnosis	Carbohydrate Deficient Glycoprotein Syndrome	Rubinstein-Taybi Syndrome	Hydrocepholus, Global Dev. Delay	Down Syndrome, Hand defect	Global Dev. Delay	Down Syndrome
Age at Diagnosis	12 months	3 months	5 months, partial diagnosis	Birth	18 months	Birth
CA ^a	30 months	34 months	21 months	12 months	25 months	10 months
DA ^b	9 months	20 months	14 months	7 months	18 months	6 months
SES	NA ^c	NA ^c	NA ^c	NA ^c	NA ^c	NA ^c
Other Children ^d	D 5, Step S 17 ^e , Step D 15 ^e	S 5, Step d 16 ^e , Step S 14 ^e	S 3	None	D 5	None

Table 3.1, Continued

Name	Joni	Rani	Tami	Lori	Suni	Boni
Number of Interviews	3	4	5	4	3	3
Ways of Coping Interview	No	No	Yes	Yes	Yes	Yes

Note. Ages reported at time of initial interviews. ^aChronological Age; ^bDevelopmental Age. ^cNO, no financial assistance, family not eligible for financial assistance programs, i.e., Medicaid, Social Security Income (SSI). ^dS = son, D = daughter. ^eNot living in household at time of study.

participated in semi-structured interviews as part of the pilot study. Their children continued to receive services through the early intervention program through the current study. Suni and Boni were recruited as study participants for the current study. They also participated in semi-structured interviews. In addition, Tami, Lori, Suni, and Boni participated in follow-up interviews. Questions for the follow-up interviews were developed from constructs that emerged during data analysis, from issues raised during interviews with the 2 new study participants, and from a questionnaire on coping. In addition, I observed mother-professional interactions between Tami, Lori, Suni, and Boni and their children's service providers as they attended the children's therapy sessions. I also conducted semi-structured interviews with the 7 observed service providers: 2 physical therapists, 2 occupational therapists, 2 speech-language pathologists, and 1 home interventionist.

Jani is a 38 year-old married Anglo-American. Her daughter, Valerie was 30 months at initial data collection. Valerie was diagnosed with Carbohydrate-Deficient Glycoprotein Syndrome, a metabolic disorder that resulted in severe feeding difficulties and chronic illnesses. Valerie is fed through a gastrostomy tube. A gastrostomy is a surgical opening made through the abdominal wall directly into the stomach into which a tube is inserted for the purpose of feeding. Jani works weekend shifts as a nurse at a hospital 35 miles from her rural home. A teenage stepson and

5-year old daughter also reside in the family home. Joni's teenage stepdaughter does not live with them. At the time of the pilot study, Valerie was receiving services from a physical therapist and a home interventionist. She previously had received speech-language services, and during the study Joni worked to renew those services. Valerie's health status is fragile, and she is highly susceptible to illness.

Roni is the 37 year-old Anglo-American mother of Steven, diagnosed with Rubinstein-Taybi Syndrome, a metabolic disorder. She works from her home as a medical transcriptionist. At the time of data collection, Steven (34 months) attended a center-based early intervention program. While at the center, Steven received developmental services for speech-language and motor concerns. Steven had also been diagnosed with a non-malignant tumor in his lung and underwent chemotherapy during the year prior to the pilot study. During the time of medical concerns, Steven's speech-language and physical therapies were provided in the family home. The family was seeking additional medical opinions regarding appropriate medical treatment of the tumor during the time of the pilot study. Other family members include Roni's husband and a 5-year-old son. Roni's also has two teenage stepchildren who do not live in the family home.

Tomi, 33, is the mother of Daniel, age 21 months at the time of initial interviews. Daniel received a diagnosis of hydrocephalus. Subsequent to

this diagnosis, he experienced chronic illnesses, feeding difficulties, and delays in motor and speech development. During the pilot study, he received services from a home interventionist, occupational therapist, physical therapist, and speech-language pathologist. Tami is an Anglo-American masters-level nurse employed part-time at a large regional hospital. Three months prior to initial interviews, Tami and her family relocated from a western state in order to access better services for Daniel. Other family members include her husband and a 3-year-old son.

Lori is a married, 24 year-old, Anglo-American mother of Megan, 12-months at the time of initial interviews. Megan was diagnosed at birth with Down syndrome and a heart condition secondary to the diagnosis. Megan underwent two heart surgeries, the first at 4-months and the second at 14-months. Megan also has a physically deformed left hand. Lori and her husband were stationed with the Army in a southwestern state when Megan was born, but following their separation from the service, the family relocated to a small town near Lori's parents and siblings. Lori manages an apartment complex and attends a local university. Megan is an only child who, at the time of initial interviews, received services from a home interventionist, occupational therapist, and physical therapist.

Suni is the 34 year-old Anglo-American mother of April who has been diagnosed with global developmental delays. Concerns for April's

development arose when she failed to meet several of her developmental milestones. At the time of data collection, April attended a developmental classroom at a local early intervention center. She also received individual physical therapy, occupational therapy, and speech-language therapy at the center. Suni is a stay-at-home mother who previously worked as a recreational therapist with adolescents and adults with developmental disabilities. Other family members include Suni's husband and a 5-year-old daughter.

Boni, 33, is the married mother of 10-month old Derek, diagnosed at birth with Down syndrome. Derek's health is good, and presently there are no health complications from his diagnosis. Derek, an only child, receives weekly visits from a home interventionist and attends individual physical therapy sessions. A speech-language pathologist and occupational therapist monitor him monthly. Boni is an Anglo-American financial analyst at a large regional hospital. At the time of Derek's birth, Boni's mother-in-law moved to the area from a distant state to provide daily care for Derek.

Though all these women are married and of Anglo-American ethnicity, there are many other variables that affect how they think, feel, and cope. I strive to collect data in the best ways to ensure that their individual voices would be heard.

Data Collection

The goal of qualitative research is to learn the meanings that participants attach to actions and events in their everyday lives. Meanings involve the symbols, referents, and relationships between different actions and events. An individual determines meaning from the significance of an action or event and the interpretation or categorization of that event based upon prior experiences. To study meaning researchers must make inferences from coding and categorizing participants' words, actions, and artifacts (Spradley, 1979). I utilized semi-structured interviews, participant observation, artifact analysis, and questionnaire to collect data.

Semi-structured interviews with mothers. I conducted semi-structured interviews with the 6 mothers. All interviews were audio taped and transcribed verbatim (Spradley, 1979). I developed the mothers' initial interview questions during the pilot study (see Appendix A) that were designed to address my study's foreshadowed research questions. I asked mothers about the feelings they experienced and the meanings they assigned to three general areas: (a) receiving diagnoses, (b) employing coping mechanisms and accessing support systems; and (c) establishing parent-professional interactions. I made slight modifications to the original pilot study questions for the current study based upon themes that emerged from the initial round of interviews (see Appendix B).

For example, when my analysis of pilot data suggested some participants' turned to others as they experienced stress in parenting their children, I added a question on social and emotional supports. When analysis of pilot data revealed mothers acknowledged positive experiences with their child, I asked the mothers to tell me the positive effects on their families resulting from their children's disabilities.

I interviewed each of the 6 participants between three and five times resulting in 22 hours of semi-structured interviews. Each hour-long interview was audio taped and transcribed verbatim (Spradley, 1979), resulting in a total of 946 pages of mother-interview transcripts.

Semi-structured interviews with service providers. I developed interview questions for the service providers to elicit their personal views of family involvement in early intervention program services (see Appendix C). I was interested in discovering providers' philosophies of family involvement, the events or experiences that contributed to their philosophies, and if those philosophies drove their service provision. I was also concerned with consistency between what the providers purport as their philosophies, the actions observed as they interact with the participants, and the mothers' views of providers' work and philosophies. I conducted seven 40-minute, audio taped, semi-structured interviews with service providers resulting in approximately 5 hours of interviews. These

interviews were also transcribed verbatim providing 167 pages of service provider-interview transcripts.

Observations. I observed parent-professional interactions for those mothers who participated in their children's therapy sessions. During observations, I took the role of a passive participant-observer (Spradley, 1980) or spectator who, though present, only watches and records what participants say, display, and do. To remain unobtrusive and not influence the mother-therapist interaction, I recorded these data in post hoc field notes. Observations yielded 56 pages of transcribed field notes. I used data from these field notes to substantiate interview data and to add dependability (Lincoln & Guba, 1985) to the study.

Artifact analysis. Artifacts consisted of additional information voluntarily provided by the mothers. I included Family Support Plans (FSP), information from Internet sources regarding specific disabilities, and other information pertinent to individual child characteristics, such as, but not limited to individual web pages, medical information, and email correspondence from parents. Analysis of these artifacts lends credibility to the study by providing an additional source of information relative to the participants' disability issues.

Questionnaire. Following initial interviews, I conducted follow-up interviews with the four mothers in the current study based upon a revised version of the Ways of Coping questionnaire (Folkman & Lazarus, 1988)

(Appendix D). This instrument contains 24 items that describe a range of cognitive and behavioral strategies people use to manage stressful demands. A principal factor analysis by Folkman and Lozorus derived eight scales accounting for 46.2% of the variance. The top three items in each subscale that had the highest loading are used in the revised questionnaire. Chronbach's Alphas for each subscale range from .41 to .65.

Respondents answered each question using this 4-point Likert-like scale (0 = does not apply and/or not used; 1 = used somewhat; 2 = used quite often; 3 = used a great deal). Thirteen of the 24 items describe adaptive coping strategies and the remaining 9 items describe maladaptive coping strategies. I used the coping questionnaire to determine how mothers classify their own coping behaviors given these 24 descriptors. Although mothers provided a numerical response, no statistical analysis was conducted on these data. Rather, mothers were encouraged during the administration of the questionnaire to detail any experiences prompted by the coping questions. I followed this procedure in order to maintain a pure qualitative methodology in this study. These data were then compared to mothers' descriptions of coping from interview data, serving to triangulate findings with another source of data. These follow-up interviews, including the administration of the questionnaire and all details provided by the mothers, were audio taped and transcribed using

the verbatim principle. As the data were collected, I implemented data analysis methods.

Data Analysis

Qualitative data analysis progressed concurrently with data collection, not in a linear fashion, but rather circularly. Themes that appeared during the analysis process suggested new avenues for interviews. I analyzed the new data from follow-up interviews to add richness to original information. I conducted my analysis using Spradley's (1979) developmental research sequence. The analysis began with domain analysis and progressed through componential analysis and eventually to taxonomic analysis.

Domain analysis. I began domain analysis with open coding, the initial process of reading data line by line to "formulate any and all ideas, themes, or issues they suggest, no matter how varied and disparate" (Emerson, Fretz, & Shaw, 1995, p. 143). Several themes emerged as I coded the pilot study interviews. These themes included "losing control," "time constraints," and "advocacy."

Domain analysis continued using the ideas or issues that emerged during open coding. I organized these ideas into domains. The name of each domain was classified as the cover term, the "name for a category of cultural knowledge" (Spradley, 1979, p.100). Included terms are a subset of the cover term. Each cover term contained at least two and

often dozens of included terms. For example, I identified "losing control" as a cover term during open coding and organized several included terms under the cover term. I included such terms as "yelling at the doctor," "crying inconsolably," and "falling apart" as examples of participants "losing control," while "being treated as an idiot" and "being ignored" were precursors to "losing control."

As a final step in domain analysis, I determined the semantic relationships that linked the included terms to the cover term. The relationship between these terms is shown through such statements as, "X (included term) is a kind of Y (cover term)." I provide semantic relationships for several of the included terms under the domain cover term "losing control" in Table 3.2.

Table 3.2

Domain Analysis Relationships

Included Terms	Semantic Relationship	Cover Term
Yelling at the doctor Crying inconsolably Falling apart	\ } Is an example of > /	Losing control
Being ignored Being treated as an idiot	\ } Is a precursor to > /	Losing control

Componential analysis. As Spradley (1979) explains, componential analysis involves "searching for contrasts, sorting them out, grouping some together as dimensions of contrasts, and entering all this information into a

paradigm" (p. 178). This analysis contrasts with domain analysis, which seeks similarities among terms. During componential analysis, I grouped included terms together under a common core term and cover term domains together under a single taxonomic category that explains the full range of meanings and actions in my data. The taxonomy displays relationships among data categories (Spradley, 1979). By sorting and grouping contrasts, I was able to develop a paradigm, or a "representation of the attributes which distinguish members of a contrast set" (Spradley, 1979, p. 177). For example, during the pilot study both "suspicion that something is wrong" and "acting on the suspicion" were steps in "becoming aware of the disability." To differentiate between these two terms, I established "suspicion that something is wrong" as "feeling," while "acting on the suspicion" was designated as an "action." This distinction was important because I wanted to determine what triggered mothers to act on their suspicions and determine whether or not their children *did* have disabilities.

Taxonomic analysis. Taxonomic analysis helped me find the overarching themes in my data and to convey a sense of the whole. Morris Opler defined a theme as "a postulate or position, declared or implied, and usually controlling behavior or stimulating activity, which is tacitly approved or openly promoted [by group members]" (Opler, 1945, p. 198). Taxonomic analysis allowed me to connect the common

experiences of 6 women who, although they never met, share binding experiences, problems, solutions, and coping strategies. While each individual story is compelling, what is most powerful is the common social-psychological problems faced by all of these mothers of young children with disabilities. During taxonomic analysis, I was able to unite the minute particulars of each mother's experiences under a common theoretical frame. The theme "Coming to Terms" represented the cognitive principle evidenced by domain and componential analysis.

Trustworthiness

Research must satisfy the research community's demand that data and findings are valid and reliable. As Kirk and Miller (1986) explain, "reliability is the degree to which the finding is independent of accidental circumstances of the research, and validity is the degree to which the finding is interpreted in the correct way" (p. 20). Guba (1981) recognized that qualitative researchers might have different perspectives from those espousing a more traditional scientific approach and suggested perspectives of "trustworthiness." The major aim of trustworthiness is to reconstruct the perspectives of those being studied by demonstrating that the researcher's interpretations of the findings are reliable. Credibility, dependability, and attention to ethical issues contribute to the trustworthiness of this study.

Credibility. I addressed validity concerns by having repeated interactions with participants in multiple settings, accessing multiple sources of data (interviews, observations, artifacts), and by further triangulating data through member checks with participants.

Member checking involves "sharing interview transcripts, analytical thoughts, and/or drafts of the final report with research participants to make sure you are representing them and their ideas accurately" (Glesne, 1999, p. 32). Each mother was provided copies of the transcribed interviews. As data analysis progressed, I informed the participants of the directions of my findings and asked for verification of their perspectives. The mothers agreed with my analysis of their perceptions. I conducted the member check interview for Joni and Rani at the end of their participation in the study. I conducted two member check interviews with the remaining 4 mothers, midway through the study, and following the coping questionnaire interview.

Kirk and Miller (1986) emphasize the importance of observing participants under varying circumstances as a way to assist the researcher in "making sense of [participants'] experiences in a language that transcends the culture-specific experience of the world of either the native or the readers"(p. 38). During the course of this investigation, I interviewed each participant on three to five occasions. In addition, I observed mothers participating in their children's therapy sessions.

Additional interactions included telephone conversations and email correspondence. For some participants (i.e., those whose participation was limited to the pilot study or those who did not enter the study until after the pilot), interaction with the researcher was limited to a matter of months rather than years. Although much qualitative research has a component of prolonged engagement, McWilliam notes, "a series of semi-structured interviews on a fairly circumscribed topic typically does not require prolonged engagement as it is commonly understood" (McWilliam, 2000c, p. 77).

Dependability. Guba (1981) used the term "dependability" to describe the consistency or reliability of qualitative research methods. He advocates the consistent use of data collection principles to enhance dependability. Kirk and Miller (1986), suggest that "for reliability to be calculated it is incumbent on the scientific investigator to document his or her procedure" (p.72). I have provided a full description of the procedures I used to both collect and to analyze data.

Dependability was achieved through collaboration with critical peers. This occurred both during the pilot study, where weekly evolution of new data was discussed with other novice researchers under the direction of an experienced researcher, and during the current study with research advisors. To further promote dependability, a member of my research committee independently read and analyzed one interview

transcript from each of the 6 participants. The two of us then composed our analysis of the narratives. Although the wording of the themes we had extracted from the narratives differed, there was agreement on the content and meaning of the themes. Because we did not conduct a content analysis of the transcripts, it was not methodologically sound to do a frequency count of responses or calculate how many mothers gave a particular response. A thematic analysis was more appropriate to my interests of describing how these 6 mothers come to terms with their child's disability. This process eliminated analytical bias and strengthened the dependability of findings.

Another aspect of dependability is reflexivity. Ball (1990) defines reflexivity as "the conscious and deliberate linking of the social process of engagement in the field with the technical process of data collection and the decisions that that linking involves" (p. 159). During the study, I assumed a deliberate role as a researcher in any encounter I might have with my research participants. I made conscious decisions as to how I presented myself to the mothers. For example, two of the mothers, Tami and Suni, participated on the early intervention program Regional Policy Council, where I served as an advisory member. It was important that I maintained an awareness of my research self as I interacted with these participants during council meetings. Dependability is also a

consideration in examining researcher biases. My subjectivity and biases are examined here as part of ethical issues.

Ethical issues. I based ethical considerations upon what may be considered the unbalanced relationship between the researcher and the participants. I asked the participants to trust me by revealing personal and intimate details of their family life. As Glesne (1999) put it

The relationships in traditional qualitative research . . . are generally asymmetrical, with power disproportionately on the side of the researcher. Consequently, researchers must consciously consider and protect the rights of participants to privacy. They must reflect on and mitigate deceptive aspects of research. (p. 122)

In an attempt to balance the disproportionate power between my participants and myself, I designed the study to meet the requirements set forth for human subjects study by the University of Florida Institutional Review Board (IRB). In addition, I adopted the following principles proposed by Spradley (1979) to ensure the ethical treatment of my participants: (a) consider participants first; (b) safeguard participants' rights, interests, and sensitivities; (c) communicate research objectives to the participants; (d) protect the privacy of the participants; (e) avoid exploiting the participants; and (f) make reports available to participants (p. 35-39).

While the IRB procedure protected the confidentiality of participants, the aspect of research deception was a further consideration. Deception can take two different forms, deliberate

commission or omission (Glesne & Peshkin, 1992). Deliberate commission occurs when researchers misrepresent their identity as researchers. All participants in this study were clearly informed of my role as a researcher. Omission occurs when the researcher does not fully inform the participants of what is being researched. In all social research, there is a fine line between providing participants with adequate knowledge of the research topic so that they can make fair and fully informed decisions to participate and withholding information that might bias participants' behavior. As Glesne (1999) explains, "the researcher's role is to observe and measure, and care is taken to keep the researcher from affecting the data" (p. 5). For example, in this study I was interested in determining how the participants cope with stressors related to parenting a child with a disability. I chose not to use the word "coping" during interviews. Instead, I asked how they managed during times of stress. By doing this, I allowed the respondents to use and then define "coping" as it naturally occurred in conversation.

In any form of qualitative research, the researcher serves as the primary data collection instrument (Bogdon & Biklen, 1992; Glesne, 1999). All interpretations are filtered through the researcher's own experiences and understanding (Emerson, Fretz, and Show, 1995; Spradley, 1979). Strict adherence to accepted research methodology is a necessary, but not sufficient, guard against research bias. Researchers must also

constantly scrutinize the research process and reflect upon their own individual subjectivity. In order to clarify possible biases, it is important for the researcher to reflect upon individual subjectivity and how it will be used and monitored during the research (Glesne, 1999, p. 32). As part of the preparation for this investigation, I examined my own perspectives, biases, and assumptions regarding the families of young children with disabilities. Although researchers seek to reduce the influence of their own personalities and beliefs, Ball (1990) notes, "the presence, the effect, and the biases and selections of the researcher cannot be removed from qualitative research" (p. 167). Yet it was important for me to check my own biases regarding families of children with disabilities to keep my individual perceptions from clouding collection and analysis of the data. I accomplished this by (a) seeking clarification from participants, (b) using member checks, (c) reflectively examining my own priorities regarding the research and (d) discussing findings with other researchers.

Researcher Biography

From July 1995 until August 1998 I worked as a speech-language pathologist as an employee of the Idaho state early intervention program providing services to infants and toddlers and their families. My training in both speech-language pathology and early childhood special education influenced my professional practice. My family-centered philosophy of service delivery had moved me from the traditional medical model often

associated with speech-language pathology to methods that more fully honored family goals, priorities, and concerns for their young children. I provided services in natural environments including homes and child-care settings. I also provided services during center-based Play Groups, where parents received instruction while the child was receiving therapies. I facilitated Parent Groups at the center, providing opportunities for parents to voice concerns.

Based upon my desire to influence agency policies regarding families and children, I volunteered as a member of the Idaho Region VII Infant-Toddler Committee. I subsequently was appointed chair of that committee. As chair, I participated at the state level as an ad hoc member of the Idaho Interagency Coordinating Council. My association with this council provided the opportunity to discuss pertinent problems facing the early intervention program with parents of young children with disabilities from throughout the state. When I left Idaho to begin my doctoral study in Florida, I again made contact with the agency administering the early intervention program to volunteer as a member of the Regional Policy Council. Once again, this association allowed me to be privy to the distinct challenges faced by parents of infants and toddlers with disabilities.

During my work and volunteer experience, I became aware of some of the stressors faced by families of young children with disabilities. I

also determined that regardless of diagnosis, no two children and no two families are the same. Despite differences, however, I also felt that certain patterns could reveal themselves that will contribute to a greater understanding of these families.

I approached this study with the recognition that I may have biases regarding the ways in which services should be delivered. During my own practice, I observed conflict among professionals regarding educational and medical models of service delivery. Indeed, from training aspects, some professionals, i.e., speech-language pathologists, occupational therapists, and physical therapists, rely heavily upon physiological aspects of development. My own training as both a speech-language pathologist and an early childhood interventionist served to temper my reliance upon the traditional medical model often evidenced in the practice of speech-language pathology. During this study, I made a conscious effort to remove any preconceived biases regarding these professions as I made observations of service providers. Every effort was made to remain objective so my biases did not impinge upon the data.

Summary

The interpretivist paradigm supports qualitative research methodology, including ethnographic methods. I designed this study to provide a forum for the voices of mothers of young children with disabilities so that others, especially service providers, can gain a deeper

understanding of the mothers' perspectives. Added insight may help service providers tailor their attitude and methods on a case-by-case basis in order to further empower families of children with disabilities.

Four of the 6 participants were involved in a pilot study, 2 of whom did not undergo further interviews because their children turned 3 years and aged out of early intervention program services. The remaining 2 mothers in the pilot study participated in observations and further interviews based upon a coping questionnaire. I then recruited 2 additional participants who met the criteria of having a child age 2 or younger currently receiving services under the auspices of the early intervention program for interviews, observations, and follow-up interviews based on the coping questionnaire. I interviewed all the mothers in their homes. In both homes and offices, I observed the interactions between those mothers who participated in their children's therapy sessions and their children's service providers; later I interviewed the service providers in their work settings. When parents provided artifacts, I included them in data analysis as well.

Data were collected and analyzed using ethnographic procedures outlined by Spradley (1979). Accessing multiple sources of data increased the validity of this study. Although I first interpreted the data through my own socially constructed reality, the provision of member checks and collaboration with critical peers ensured that I did not skew or

misrepresent participants' realities. The trustworthiness of the data was further guaranteed through repeated interactions, collaboration with critical peers, reflexivity, and clarification of researcher bias. In chapters 4 and 5, I report the results of data analysis.

CHAPTER 4 FINDINGS PART 1: RECEIVING DIAGNOSIS

Introduction

Prospective parents eagerly await the birth of a child full of expectations for the future. Their hopes and dreams for the child are challenged when the child is born with or later acquires a disability. Infants and toddlers with disabilities may be eligible for early intervention services through Part C of the Individuals with Disabilities Education Act (IDEA). This program provides comprehensive services for infants and toddlers (birth through age two) with special needs and their families. A major component of family-centered early intervention is to increase child, parent, and family functioning by empowering families to make decisions regarding their children's interventions.

Turnbull and Turnbull (2001) recognize the "birth and early childhood" stage as one of the stages in the family systems framework (Turnbull, Summers, & Brotherson, 1984). They identify two challenges that families encounter during this stage, discovering and coming to terms with exceptionality and participating in early childhood services. This study focused exclusively on mothers during the birth and early childhood life

cycle. Thus, these data contributed to a more microscopic view of this life stage.

In this study I examined the experiences of 6 mothers of infants and toddlers receiving Part C developmental services. I used such qualitative methods as interviews, observations, and artifact analysis. I investigated several events within the early childhood life cycle that may influence how mothers came to terms with young children's disabilities. These events included receiving diagnoses, employing coping mechanisms and accessing support systems, as well as establishing parent-professional relationships. The goal of the study was to find out how six mothers learned about, came to understand, and responded to the evolving realities of having a child with disabilities.

In this and the following chapter I report the findings of my data analysis. I analyzed parent and service provider interviews and observations of parent-professional interactions guided by five research questions:

1. How did these mothers respond to the initial disability diagnosis?
2. What did mothers perceive to be the long- and short-term implications of the diagnosis for their child, their families, and themselves?
3. What types of support did mothers seek, find, and receive for their child, their families, and/or themselves?
4. What qualities did mothers value in professionals?

5. What changes did mothers suggest to early intervention services?

My analysis of interview and observation data revealed five significant sub-stages within the birth and early childhood life cycle stage that these 6 mothers experienced in the process of coming to terms with their child's disabilities: (a) Becoming Aware: Something is Very Wrong; (b) Discovering, Seeking, and Finding Services: Awareness of Early Intervention; (c) Enrolling in Services: Access to Early Intervention; (d) Learning the System: Delivery of Services; and (e) Looking Back: Suggestions for Improvement of Early Intervention. Permeating all of the five sub-stages was the mothers' focus on learning better ways to cope. I provide the findings to the first sub-stage in this chapter.

In Table 4.1, I display the relationship between the sub-stages and the research questions. The sub-stages do not represent strict steps in a linear process. Rather, due to the complexity of living with a young child with a disability, the stages often intermingle. For example, I found that the mothers might be facing newly discovered challenges of their children's diagnoses at the same time they were attempting to learn the rules and requirements of the early intervention system. In this situation the mothers were coping not only with their children's developmental challenges, but also with the complexity of the developmental services system. The complex relationship among the sub-stages was evidenced

Table 4.1

Research Questions and Significant Sub-Stages

How did the mothers respond to the initial disability diagnosis?	What did the mothers perceive to be the long-and short-term implications of the diagnosis for their child, their families, and themselves?	What types of support did the mothers seek, find, and receive for their child, their families, and/or themselves?	What qualities did mothers value in professionals?	What changes did mothers suggest to early intervention services?
Becoming Aware: Something is Very Wrong	Becoming Aware: Something is Very Wrong	Discovering, Seeking, and Finding Services: Awareness of Early Intervention	Looking Back: Suggestions for Improvement of Early Intervention	Looking Back: Suggestions for Improvement of Early Intervention
		Enrolling in Services: Access to Early Intervention		
		Learning the System: Delivery of Services		

as these mothers recounted the multiple tasks faced in becoming aware, accessing developmental services, learning the system, and evaluating professional and personal aspects of the process. The overlap of sub-stages added to the mothers' difficulties because just as these women were successful in negotiating one task another task appeared. For example, as mothers came to understand the overall diagnosis, they slowly realized that their babies would face severe and life-long medical needs and developmental challenges.

The sub-stages are not always sequential and individuals cycle through (and recycle through) the sub-stages at different speeds and sometimes in different order depending on their situation. But the sub-stages themselves are consistent and therefore useful to anyone who wants to understand the process and better serve mothers with children with disabilities.

This chapter focuses on events surrounding diagnosis of disability. I begin by providing an overview of each mother's experiences. These stories provide a basic introduction to the unique features of each of these families and illustrate the different sub-stages. Next I present the sub-stage "Becoming aware: Something is very wrong" with findings addressing the research questions, "How did the mothers respond to the initial disability diagnosis?" and "What did mothers perceive to be the long- and short-term implications of the diagnosis for their child, their

families, and themselves?" Along with this sub-stage, I include findings demonstrating how these mothers coped with their children's diagnoses. I present findings from the other four sub-stages in chapter 5, Participation in Early Intervention Services. Throughout both chapters, I reference participant quotations using the participant's initial, the interview number, the page number, and the line of the page where the quotation began.

Mothers' Stories

Joni

Joni, a 38-year-old nurse, gave birth to Valerie in a Florida hospital approximately 40 miles from her rural home. Although Joni's pregnancy had been uneventful, within five hours of birth, Valerie began evidencing problems. She had passed meconium and ended up with pneumonia. In addition, she had Erbbs Palsy in her right shoulder.

Joni initially suspected that the soreness in Valerie's shoulder interfered with her ability to nurse. Joni's doctor prescribed a feeding machine at night but after several months Valerie gained little weight. Doctors suspected that Valerie's liver was not functioning well but were at a loss to explain why.

When Valerie was 9 months old, doctors surgically inserted a G-tube. A G-tube is a device that is inserted surgically through the stomach wall, directly into the stomach. At pre-determined intervals, oftentimes at night while the person is sleeping, a specially balanced feeding solution is

dripped into the tube either by gravity or by pump. Following this surgery Valerie began to gain weight. Unfortunately, the first G-tube malfunctioned and 2 months later doctors brought Valerie back to the operating room and inserted a new tube. During this second surgery the doctors also performed a liver biopsy, which was sent to the National Institute of Health for analysis. Three days following the surgery Valerie began to vomit blood, and concerned doctors admitted her to the Intensive Care Unit. Doctors operated to cauterize her stomach, but the bleeding continued and within 48 hours performed a second surgery for further cauterization. Following the surgeries, Valerie experienced breathing difficulties caused by streptococcus and staphylococcus infections so doctors placed her on a ventilator. Valerie received massive blood transfusions (enough to replace her entire blood supply) and slowly stabilized.

After a frustrating year of uncertainty, doctors finally diagnosed Valerie's health problems. However, Joni's confusion continued as she struggled to come to terms with the diagnosis. Doctors called Valerie's condition Carbohydrate-Deficient Glycoprotein Syndrome (CDGS), which they defined as a metabolic disorder that results from abnormal synthesis of sugar groups that are parts of glycoproteins ("sugarproteins"). Initially Joni was so relieved that her daughter had survived her several surgeries that the doctors' diagnosis seemed of secondary importance. Joni's

feelings would change in time, but for the moment, Valerie was alive and gaining weight and Jani's anxiety eased.

Four or 5 weeks later, as Valerie's condition stabilized, Jani turned her attention to her child's diagnosis. Looking for help and information, Jani contacted Danna H at the National Institute of Health (where Valerie's liver tissue sample had been sent for assessment). Coincidentally, Danna's son also has CDGS. Through ongoing conversations with Danna, Jani slowly came to understand the full weight of Valerie's diagnosis. During interviews with me, Jani explained she had learned from Danna that Valerie faced a life of

almost constant problems. When you get past the first year and failure to thrive, the bleeding tendencies, pericardial effusion [fluid around the heart], then you are looking at seizures and strokes around age four with bumps on the head. Low-grade temps. Then the myelin sheaths [protecting the neurons in the brain] start to deteriorate, so anything [she has] gained so far as the use of [her] legs is probably going to be lost. [She will likely have] scoliosis, capasis. No puberty. Can't speak to be understood except by family members. Retarded, [she] will probably never be out on her own. (J1,19,16)

Jani was overwhelmed by the prognosis, but was determined to help Valerie reach her developmental potential. Jani had first made contact with the Infant-Toddler Program personnel just prior to Valerie's medical crisis. They scheduled an evaluation, but Jani was unable to keep the appointment due to Valerie's hospitalization. An early interventionist from the program made contact with the family while

Valerie was hospitalized and explained to Jani the services the Infant-Toddler Program could provide.

Valerie was 13 months old at the time of her initial evaluation for early intervention services. Subsequent to the evaluation, she had received weekly home-based developmental and physical therapy services. Center-based weekly occupational, and speech-language therapies were later added. However, these services were often interrupted by Valerie's chronic health problems. Jani expressed to me same concerns regarding the center-based services, both because of the distance she had to travel to receive them and because of problems rescheduling when Valerie fell ill. By the end of her participation in my study, Valerie was approaching 3 years of age and Jani was beginning to make preparations for Valerie's anticipated transition to school-based preschool services.

Rani

Rani gave birth to Steven in a local Florida hospital following an uneventful pregnancy. She was 37 years old at the time of interviews and was employed doing medical transcription in her home. During Steven's initial newborn exam, the pediatrician noted several concerns including a very hairy back, small cyst at the base of the spinal column, high arched palate, broad thumbs, undescended testicles, atrial septal defect (a defect in the wall between the two upper chambers of the heart), and

very low muscle tone. Based upon these indicators, the pediatrician requested a genetics consult. At 2-days-old, Steven spiked a fever and was admitted to the Newborn Intensive Care Unit. The doctor ordered spinal taps, but found no specific reason for the high fever. After 10 days, Steven stabilized and was released from the hospital.

Rani and her husband received the results of Steven's genetic consult when Steven was nearly 3-months-old. The geneticist told them that even without definite DNA proof, all indications pointed to Rubinstein-Taybi Syndrome, which is caused by a deletion on the 16th chromosome. Rani recalled how difficult it was sitting and listening to the geneticist's detached presentation as he read off a list of potential future concerns, including mental retardation. The doctor was accompanied by a group of medical students, and when interviewed Rani told me she felt the disclosure of Steven's diagnosis was handled poorly

I had a horrific time with it. Just the way it was presented, it was very matter-of-fact. It was just "here it is, this is what I think it is, we are relatively sure." Of course, how did I expect it to be? How can you present something like that? [Yet] If you are a person in that position, you have an obligation to the parent to have done your homework before you present something to them, as for as saying, "here are resources, I looked online, and here is a parent's support group, and I have a counselor here who would like to talk to you, or if you would like to talk to him, I have this setup for you." (R2,2,8)

Three months later, frustrated and worried that nothing was being done to help Steven meet his developmental milestones, Rani voiced her continuing concerns to her pediatrician. The pediatrician suggested a

developmental evaluation. Based upon this evaluation, Steven qualified for early intervention program services, and Roni began taking him to weekly physical and occupational therapies in addition to weekly visits by a home interventionist. These services continued until Steven turned 15 months, at which time he began receiving services in an early intervention center-based program. Just prior to his second birthday, doctors diagnosed Steven with plasma cell granuloma—a mass in his right lung. Although the tumor was non-malignant, doctors prescribed chemotherapy in attempts to shrink it. Because of his fragile medical status during this time, he received his developmental therapies in his home for several months. Although the granuloma remained unresolved, Steven regained his strength and his services resumed at the early intervention center. Steven's doctors were urging the family to consider a lobectomy, but Roni indicated that she would continue to seek alternate opinions regarding Steven's care. At the time of the study, Steven was receiving developmental, speech, occupational, and physical therapies. As his third birthday approached, Roni was beginning to visit area schools in anticipation of Steven's transition to school-based services. At this point her participation in the study ended.

Tami

Tami, a 33-year-old nurse, had an uneventful pregnancy before delivering Daniel in a southern California hospital. At two weeks, he was

readmitted to the hospital with a fever and ear infection. He underwent a lumbar puncture at that time in an effort to determine the infection's cause. The ear infection did not respond to a series of antibiotics, so Daniel underwent surgery for pressure equalizing tubes at 4 months. Three weeks following the surgery, Daniel seized and was again hospitalized. Physicians ordered a CAT scan, which showed hydrocephalus. Hydrocephalus is an abnormal accumulation of cerebrospinal fluid (CSF) within cavities called ventricles inside the brain. As the CSF builds up, it causes the ventricles to enlarge and the pressure inside the head to increase.

Despite the diagnosis, Tami felt that more was wrong. Even with the ear tubes, Daniel continued having chronic ear infections, during which time he went through 13 different antibiotics in an attempt to control the infections. Other problems, including reflux, sinusitis, and seizures, continued. At 9 months, he was again hospitalized and underwent more testing, including a kidney ultra sound, Computed Axial Tomography (CAT) scan, echocardiogram, upper gastro-intestinal testing, an electroencephalogram (EEG), and electrically evoked auditory testing. While hospitalized, Daniel contracted rotavirus, which resulted in severe vomiting over the five days he was hospitalized. Following these tests, Daniel was diagnosed with lower esophageal weakness and a 40 dB bilateral conductive hearing loss. Also at this time, Tami began to realize

that Daniel had low muscle tone throughout his body and was able to convince professionals that he should be referred for a developmental assessment.

Due to his hearing loss, Daniel and his family began receiving services at the not-for-profit John Tracy Clinic in Los Angeles. While Daniel was receiving twice weekly interventions, Tami and her husband participated in parent support groups. On the third day, the entire family participated in a "demonstration home," where interventionists provided support to the family to encourage Daniel's interactions within a home environment. However, when Daniel's health improved, and his hearing function became normal, he was released from services of this clinic. The social workers of the clinic did, however, inform Tomi about the Port C early intervention program.

* In an effort to accelerate the process, Tomi contacted both the early intervention program and a local private developmental center that would accept insurance. After considerable delays, Daniel received a developmental assessment through the California Port C early intervention program that qualified him for developmental and occupational therapy services. He began receiving home-based infant stimulation services of one year. Still concerned about Daniel's communication, Tomi requested a speech-language evaluation at 15 months. Daniel subsequently qualified for both speech-language and

physical therapy services. Despite Part C's requirement that there be no waiting list for services, Tami waited four months for these additional services and, due to professional shortages, nothing was being provided in the interim.

Frustrated with the system, Tami began calling the early intervention program offices in different states to determine where she might be able to access the fullest array of services for Daniel. Her husband had just graduated with his bachelor's degree and the family could relocate. Tami's father and stepmother lived in Florida, so it was one of the states that she researched. The person she contacted at the early intervention program in Florida took Daniel's intake information over the phone and indicated, based upon that information, that Daniel would be guaranteed developmental, occupational, physical, and speech-language services. Less than 2 weeks after this call, Tami and her two children were on a plane to Florida. Her husband sold their California home and followed a month later.

Once in Florida, Daniel immediately began receiving weekly visits from a home interventionist. Physical therapy, speech-language therapy, and occupational therapy evaluations were completed within two weeks of his arrival. Based on these evaluations, Daniel qualified for twice-weekly sessions with each. Daniel began receiving private physical therapy services the week following his evaluation. Within another two

weeks, his private occupational and speech-language services began. This schedule of therapies continued until four months later, when Daniel turned two years of age. At that time, Tami placed Daniel in an inclusive child-care program where he received services from the same home interventionist. He continued with the same private occupational, physical, and speech-language services. The early intervention program covered all costs. Daniel continued to experience frequent medical problems and at 29 months underwent surgery to have a shunt implanted to relieve the fluid buildup around his brain resultant from the hydrocephalus. His medical status improved significantly and he continued to receive services at the inclusive childcare setting. These services continued until his third birthday, at which time he was to transition from the early intervention program into school-based services. Tami was preparing for this transition process at the end of her participation in this study.

Lari

Lari, a 24-year-old student and apartment manager, was stationed with the U.S. Army in Texas at the time of Megan's birth. Megan was blue when born, and doctors immediately expressed concerns regarding her heart. When Lari's husband went to check on Megan's status, a nurse informed him that they suspected Megan had Dawn syndrome. That same day, she was transferred to a hospital in San Antonio, three hours

away from her parent's home, due to mitral valve heart problems. While hospitalized, tests were done that confirmed Megan had Down syndrome. She was released when 1-week old.

Referrals made from the hospital allowed Lori to become enrolled in the military's Exceptional Family Member Program (EFMP). It was through EFMP that the family was informed about early intervention program services. Megan began receiving weekly home visits from a home interventionist at 2 months of age and over the next 2 months began receiving physical and occupational therapy services as well.

Lori's immediate concerns for Megan, however, were to keep her healthy and gaining weight. She experienced trouble sucking and swallowing due to generalized weakness from her heart problems. At 4 months, Megan was again admitted to the hospital where she underwent surgery to repair the valves of her heart.

When Megan was 6-months-old, Lori completed her enlistment in the army and was honorably discharged. The family chose to move back to Florida, close to family. Lori's mother has a nursing background, and she helped Lori and her husband understand the implications of Megan's diagnosis. Once settled in Florida, Lori made contact with the local early intervention program and Megan once again began receiving occupational and physical therapies and weekly visits from a home interventionist. In addition, Lori received support and information from

Hape Haven, a center specializing in children with Dawn syndrome. During this time, Megan experienced chronic ear infections and at 10 months had surgery for tubes to relieve the pressure building up in her middle ears.

Megan's heart problems resurfaced at 14 months, and she once again was hospitalized for surgery on her mitral valve. Although happy with the cardiac surgeon, Lori and her husband found the post-op nursing staff very resistant to their involvement in Megan's care. This differed from their experience in Texas, where they were encouraged to assist with feedings and provide comfort following Megan's initial heart surgery. Nevertheless, Megan responded favorably to the surgery and was released after 10 days. Lori noted vast improvement in Megan's developmental skills following the surgery.

At 18 months Megan stopped receiving services from a home interventionist and began receiving developmental services at the local early intervention center. Although Megan received occupational, physical, and speech-language therapies as part of her services at the center, Lori opted to keep her in private-pay occupational, physical, and speech-language as well. These private services were important to Lori since they were scheduled during a time when she could participate with Megan in the therapies. The early intervention center was experiencing many staff changes at the time Megan began attending. Lori felt that

these changes resulted in a lack of communication between parents and the staff. Because of these concerns, Lori began investigating some other placement options. At the end of her participation in the study, she was considering placing Megan in an inclusive private childcare center.

Suni

Suni, a 34-year-old stay-at-home mother, has a career background in recreational therapy. She and her family lived in Illinois at the time of April's birth. When April was born, doctors expressed some concern that the back of her skull was uncharacteristically flat. She underwent a Computed Axial Tomography (CAT) scan at about 4 weeks. Doctors then indicated that she was neurologically intact, and that her problems were not medical but only cosmetic. The family relocated to Florida when April was 15-months-old because of a job opportunity for the father.

Although some of April's developmental milestones occurred as expected, Suni had concerns. April was nearly 17 months before she began to walk. Suni noted that it seemed to take a lot of effort for April to get her muscles to work. In addition, she did not seem to be developing speech and language skills. Suni discussed these concerns with April's pediatrician, who suggested a developmental evaluation if things did not change by the time April was 18-months-old. This evaluation eventually showed a substantial delay in communication and April qualified for early intervention program services. However, despite the federal requirement

that there be no waiting list for services, April's initial therapies were delayed two months because there were no openings in the program. She eventually began receiving weekly visits from a home interventionist, and Suni drove her to a local early intervention center for once a week speech-language therapy.

After two months of home-based services from the home interventionist, April was referred for more intensive services at the local early intervention center-based program. She began attending the center two mornings a week for developmental therapies. Once in the center, both physical and occupational therapists administered assessments of her motor abilities. The results of these assessments indicated that April had low muscle tone throughout her body. Additionally, Suni had ongoing concerns regarding April's eating habits. Although she had managed well on baby foods, once "chunkier" textures were introduced into her diet, April began to gag, and eventually refused to try new foods. The occupational therapist suggested that April might have sensory integration problems in addition to the low muscle tone concerns. Based upon these evaluations, April began receiving both physical and occupational therapies on a weekly basis. Her schedule of attendance in the developmental classroom was also increased to four days a week.

Although pleased that April was receiving services, Suni worried about the segregated nature of the early intervention center. She felt that April would make more dramatic improvement in her speech-language abilities by interacting with typically developing children. Suni began investigating other settings for services and by the end of the study had secured April a place in an inclusive child-care setting. April's IFSP was amended so that the same interventionists who had been serving April at the segregated early intervention center would provide weekly occupational, physical, and speech-language services to her in the new setting.

Boni

Boni, a 33-year old financial analyst, works at a large regional medical center. Previously diagnosed with infertility problems secondary to endometriosis, she delivered Derek at a local Florida hospital after an uneventful pregnancy. Immediately following his birth, the nurse practitioner expressed concerns that Derek may have Down syndrome. Although Boni had undergone pre-natal amniocentesis testing, the results gave no indication of Down syndrome. Derek is a healthy child with none of the concerns common for children with Down syndrome such as heart, vision, or hearing problems.

The pediatrician quickly referred Derek for physical therapy because of problems with the muscle tone in his neck. Derek received

these therapies every two to three weeks. The pediatrician also gave Boni the name of two mothers of children with Down syndrome. Boni soon telephoned these mothers, who informed her about the early intervention program and encouraged her to make contact for an evaluation. Boni called the early intervention program in September when Derek was 2-months-old, and she was informed that it would be offered the first of January before the evaluation would be done. A coworker with a child with autism told Boni that offered a referral to the early intervention program, under federal law, evaluations had to be conducted within 45 days. Armed with this understanding of the law, Boni contacted a few people, using her contacts at the medical center, to get an earlier appointment. Derek qualified for services and started receiving weekly visits from a home interventionist the next month. Derek also continued physical therapy. These services were originally covered by Boni's private insurance, but once Derek became eligible for the early intervention program, that program began paying the insurance deductible.

When Derek was 6-months-old, Boni and her husband, accompanied by their home interventionist, took Derek to Hope Haven, a special facility for children with Down syndrome in Jacksonville. There they received an abundance of information about Down syndrome and Derek underwent speech, occupational therapy, and physical therapy evaluations. Based upon recommendations from Hope Haven, when

Derek's IFSP was reviewed following six months of services, monthly monitoring of speech and occupational therapies were added to his plan. Also at that time, Derek began more frequent weekly physical therapies. Derek will continue to be seen at Hope Haven annually. These services were all in place at the end of Boni's participation in the study.

Summary of Mothers' Stories

In this section, I provided an overview of each mother's distinct story. These stories illustrate the specific medical and developmental challenges 6 mothers of very young children faced. Although the stories are individual and unique, each mother was involved in similar events while caring for her child that required her to stretch beyond previously demonstrated physical and emotional capabilities. Through the sub-stages of (a) becoming aware; (b) discovering, seeking, and finding services; (c) enrolling in services; (d) learning the system; and (d) looking back, each mother progressed in her ability to come to terms with her child's problems. The incredible resilience of these women grew more evident as they became adept in calling upon coping strategies and support systems to help them meet current and emerging challenges. These stories make apparent the complexity of the overlapping sub-stages each mother experienced. At the same time that they became suspicious regarding their children's medical and developmental status, they had to simultaneously seek services and learn how to navigate the

early intervention system. In the next section, I report on findings relative to the mothers' initial concerns that something is wrong.

Becoming Aware: Something Is Very Wrong

The mothers' experiences during the sub-stage of Becoming Aware were complex—from recognizing their children's developmental disabilities to searching for diagnoses to eventually receiving those diagnoses. Although each of the participants' experiences was unique, attributes emerged at this stage in their experiences. The common attributes were clustered into (a) suspecting that something was wrong with their child but not knowing what, (b) acting on their suspicion and pushing doctors to attend to their concerns, (c) receiving the diagnosis, and (d) coping with the diagnosis.

Suspecting That Something Was Wrong But Not Knowing What

The mothers in this study became aware of their children's diagnoses through various means. For some of the mothers, this suspicion that something was wrong lasted only a few hours or less; for others, the suspicion lasted several months. Despite the different time frames, each mother experienced anxiety when faced with the suspicion that her child may have medical or developmental problems. The length of time the mothers had suspicions was an important variable, but not the only factor for these mothers. The amount of support received from medical personnel in determining the children's developmental status also varied.

Figure 4.1 illustrates the interaction between time and support in detecting the children's medical and developmental problems. Three of the mothers, Boni, Lori, and Rani, received early detection of their children's medical and developmental problems by medical personnel. Joni and her doctors had suspicions at Valerie's birth that there were medical problems. The detection of a specific cause, however, required additional months. The other two mothers suspicions developed and increased over time. Despite their ongoing suspicions, Tami and Suni both had to press medical personnel to support them in their quest to determine their children's problems.

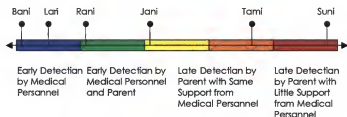


Figure 4.1 Detection Timeline and Support

Early Suspicions

Despite the fact that they had undergone uneventful pregnancies, Boni, Lori, Rani, and Joni each became suspicious that something was wrong with their babies within a few hours after their births. Boni became concerned when the "nurse practitioner . . . told me, within five minutes of [Derek's] birth [that she suspected Down syndrome]" (B1,3,12). As Lori

explained, "they didn't bring [Megan] to me [following her birth]"

(L1,20,8). Rani's concerns began when the pediatrician visited her after Steven's initial evaluation the morning following his birth

The pediatrician went in to do his normal neonatal check. She noticed that there were just some little things . . . Just a lot of little things that in and of themselves, if they existed independently might not have made her think anything, but together [they worried her]. (R1,11,4)

Jani first had suspicions five hours following Valerie's birth because, "She had passed meconium, she ended up with pneumonia . . . she wasn't feeding well" (J1,2,3). Although medical personnel did not immediately address these suspicions, Jani had an underlying uneasiness about Valerie's status. Thus a time that should have brought only joy to the mothers was colored by concerns for the future health and development of their children.

Long-term Suspicions

Tami and Suni's did not suspect that anything was wrong with their children at the time of birth. Tami explained why it took her longer to act on her suspicions. "The interesting thing is that [Daniel's older brother] had a lot of the same [ear infection] stuff that Daniel had, so a lot of what Daniel had we kind of ignored at first" (T1,2,2). After months of watching lulls in her baby's development, however, Tami grew concerned. "I just felt that he was changing color, and I felt that he was making funny noises in the middle of the night, gasping and all" (T1,4,3). She discussed her

worries with doctors but had difficulty convincing them that something was wrong. Likewise, Suni's suspicions regarding April's development emerged when her baby was 16-months-old, much later than that of the other mothers.

She was developing pretty normally. She was delayed in some things, but not delayed enough that it was something that called our attention to it. She crawled on time. She didn't walk. She walked at 17 months. So it wasn't so late. But then the speech [concerns] came up and we noticed that when she went to push things, she had to push really hard to get her muscles to work. So we started to see the law tone generalized. (S1,5,17)

Regardless of whether the time of suspicion lasted minutes, hours, or months, the anxiety and unsettled nature of these mothers' suspicions was a constant until a diagnosis was made. The continuous growing of the suspicions caused the mothers to ask questions and demand explanations so they could either be reassured or instructed how to help their child.

Acting on the Suspicion and Pressing Doctors to Attend to Concerns

Although the six mothers in this study all came to their suspicions regarding their children's medical and developmental status in different ways, once the suspicions were raised, the mothers acted quickly. All of the children's developmental concerns appeared to be closely aligned with health problems, so logically the mothers turned to medical practitioners for answers.

Two of the mothers, Bani and Lori, did not have to press doctors to attend to concerns. Rather, the medical professionals expressed opinions

that their children may have problems. The medical practitioners initially indicated to Bani the possibility that Derek may have Down syndrome. "My OB and [Derek's] pediatrician consulted on the situation and determined that they needed a blood test . . . because lots of children have some of the traits (B1,6,15). Lari worried that something was wrong when nurses didn't bring Megan to her after immediately after birth. Worried, she asked her husband to find out when they were going to bring her the baby. She explained, "He went and asked, and they said, 'Well, we think your baby has Downs, so she is in the NICU'" (L1,20,10).

Despite the fact that there were concerns at birth, Rani and Joni had to wait or push for additional testing. Rani's son Steven had been referred for genetics consult following his birth, yet the diagnosis was not forthcoming. "I kept hounding [the geneticist] to find out what. I know he was busy, but this is a crucial thing" (R2,1,21). Rani discussed her increasing stress and mounting concerns in the first few weeks after Steven's birth

Every time I would go in to have his milestones evaluated, that was very stressful just to know all of a sudden that the pediatrician doesn't go – she puts the milestone charts away after a while. She said, 'we just can't go by those anymore'. And that was very heartbreaking. (R4,11,3)

After being released from the hospital, Jani had continuing concerns regarding Valerie's growth and development. When the feeding concerns evidenced at birth continued, she indicated, "I was

pushing her as far as I could push her to help her gain weight . . . [She was on a] feeding machine at night . . . We had tried several formulas, and nothing worked" (J1,4,14). Even the medical professionals recognized the futility of some of their efforts

They knew her liver wasn't functioning; they didn't know why, we didn't have a diagnosis. And they said they couldn't fix whatever was wrong with her. But they could at least [help] her nutritionally [by inserting a g-tube]. . . . And we told them while they were in there, they could get their liver biopsy [to aid in the diagnosis]. (J1,5,13)

Tami also sought help from medical professionals in an attempt to act on her growing suspicions that Daniel's problems were serious. However, she received no support. She explained, "I had enough clarity . . . to know that I was right . . . [I knew] there was something wrong with Daniel. That there was something more wrong with Daniel than what everyone was admitting" (T1,7,12). She described her frustrations with doctors

I'd been a nurse for 13 years when Daniel was born. . . . I have learned ways of suggesting things that made it seem like it was [the doctor's] idea. I really have a lot of finesse with physicians. But as a parent, these same tactics didn't work. They didn't pick up on my cues. I was trying to carry on a physician-nurse relationship, and it wasn't working as a parent. I had to get rude. I had to be demanding, I had to get nasty. I had to ask the same question 20 times until they really answered it. As a nurse, I have never had to do that. I have always been able to get the information I wanted by kind of beating around the bush or stroking them positively, "you know, you just have so much knowledge [sarcastic tone]." But I tried and they wouldn't answer me. They would treat me like an idiot. They were condescending. (T,2,24,16)

Likewise, Suni had frustrations in discussing her mounting concerns about April's development. She looked for answers through medical channels, "our pediatrician said if she was not saying more words by 18 months, we would get her evaluated" (S1.6.10).

Even after acting on their suspicions and turning to medical professionals for answers, these mothers needed more. Some of the answers they received were ambiguous. They wanted to pinpoint the problem and to get a prognosis from their doctors regarding future implications. In order to do this, they each felt the need for a specific diagnosis.

Just as the time between suspicion of medical or developmental concern and acting on that suspicion varied for the six mothers, the time it took before they received a specific diagnosis also differed, as did the different methods mothers used to arrive at a diagnosis. Finally, the levels of relief in knowing the specific diagnosis ranged from mother to mother.

The search for their child's diagnosis involved genetic or tissue testing for 4 of the 6 mothers. For these 4 mothers, doctors' concerns alerted them to additional problems by suggesting that further diagnostic testing was needed. Bani's and Lori's circumstances were similar. Based upon presenting characteristics, the pediatricians attending their children at birth recommended to both families that the diagnosis of Dawn syndrome be verified through genetic testing. For these mothers, testing

confirmed the diagnosis by the time they were released from the hospital. Rani's situation was similar. She explained, "[The pediatrician] thought that we should see the geneticist, so she called genetics consult to come over" (R1,14,9). Although Rani and her husband consented to genetic testing at the time of Steven's birth, the results at the genetic consult were not available for almost 8 weeks. Jani's doctor, too, had suggested that genetic testing be done to determine Valerie's condition. However, this family was reluctant to pursue the testing due to Valerie's fragile medical status. Finally, knowing that Valerie would be undergoing surgery for a G-tube, they consented. Jani indicated, "they sent [the liver biopsy] off. And Dr. C. in New York came back and said it was a metabolic disorder" (J1,5,21).

The circumstances for Tami and Suni differed. These mothers initiated concerns with the doctors and worked hard to get the professionals' attention to the ongoing problems. Neither Tami nor Suni were offered genetic testing. Only after Tami observed her son Daniel suffer a seizure did the doctor order a CAT scan. She explained, "This was the first that I got the diagnosis at [hydrocephalus]" (T1,5,14). However, this diagnosis didn't answer all her questions regarding her child's health problems, so she searched for a more complete diagnosis.

They were admitting that he had hydrocephalus, but that really wasn't enough . . . They were admitting he had chronic infections. He was having reflux through his nose. That means there is something wrong, and they had no cause for it. And then it turns

out he has a bifid uvula . . . and he has a webbed toe . . . he had bilateral retroflected pinkies. And my point was, I've been [nursing] for a while, and once you have three funky things on a kid, for lack of a better word, you start looking. If you have three structural abnormalities, you should start checking on the heart and the kidneys . . . once you've got a few things going, there is some chromosomal defect, possibly. And no one wanted to look. (T1,7,17)

Similarly, despite Suni's concerns that April was not developing as was expected, no testing was offered. Her pediatrician in Illinois adopted a "wait-and-see" attitude. It was not until the family moved to Florida and Suni persisted in explaining her concerns to new medical personnel that a physician finally made a referral to the early intervention program. Suni was somewhat unsettled with April's diagnosis of "global developmental delays." She was concerned that this uncertain diagnosis did not provide the family with a clear understanding of what April's capabilities might be.

April appears to be a typical child. Although I am glad some of the stigma that is associated with syndromes isn't something we have to face, I still worry that people will expect her to function at a certain level, and that level may be difficult for her. This all ties in with having a more specific diagnosis. That way it would be easier to explain some of her difficulties to others. I guess we'll just keep searching. (S3,18,5)

The search for a diagnosis was the initial step for all these mothers in coming to terms with their children's developmental problems. The methods used to determine a diagnosis ranged from genetic testing to other medical testing to waiting to see what developed. Whether or not the children had received medical diagnoses, the mothers all recognized

that their children's problems would likely result in a variety of developmental delays.

Receiving the Diagnosis

Receiving the diagnosis of a chronic disease, syndrome, or developmental disability may result in a variety of responses. For each of these mothers, the diagnosis was completely unexpected. Both Bani and Lori had undergone prenatal testing. Bani explained, "I had the blood test; but it came back negative—that everything should be fine. So we were very surprised" (B1,3,7). Lori also was surprised at Megan's diagnosis of Down syndrome

We did the tests . . . the triple screen blood work where they test for Down syndrome and spina bifida. . . and it came back normal. We did a late ultrasound, to see her features, and all of that came back normal. Her size, her heart, everything, according to the ultrasound, was normal. And we had her, and she wasn't. (L1,23,7)

Although both Bani and Lori received initial medical diagnoses of Down syndrome at their children's birth, neither had anticipated any difficulties. Therefore, their reactions were of shock and pain. Bani explained

The first [thought] was, "oh my God, how am I going to take care of this child?" Just the whole level of shock, and then numbness started to come. And then the image . . . I remember visiting my grandmother in the nursing home. I remember there was a severely retarded man there. And that was the image I thought of. All he could do was spit, and he just sat there. He couldn't communicate; he just sat in his chair the whole time (B1,3,17). I think [both my husband and I] were just in shock. It was hard, but I think we were both in shock. I look back on that time; I don't think I cried for a day. Plus, the whole bit with meds, it was really surreal. And we were exhausted; it was 2:00 in the morning. But it was the most difficult experience we have had together. (B1,22,17)

Lori described her reaction to being told Megan had Down syndrome and heart problems as "like she had died. Like she hadn't even been born [Lori starts to cry]. That was tough. That was rough – that day was rough. It was a really hard day" (L1,26,13).

Following an uneventful pregnancy, Rani's pediatrician indicated that something might be wrong after Steven's initial neonatal exam.

I expected it to go just like it did with [his older brother] . . . [My pregnancy] was uneventful. I did all the blood work and everything had been fine. All the ultrasounds were normal and nothing was out of the ordinary . . . [He had] normal weight, normal birth. I didn't take or do anything during my pregnancy. It was normal - there wasn't anything that I would have thought, 'gosh, this was a risk factor'. I took my vitamins and followed the rules, so to speak. (R1,11,16)

Weeks passed before the geneticist delivered the official diagnosis.

Despite having a premonition that the news would not be good, Rani was not prepared for the full impact of the diagnosis

I had a horrific time with [the diagnosis]. It was pretty heartrending, to be very honest with you—I cried (R2,2,16). I just felt like a wind had swept through and taken everything out. It was horrible—I can't even verbally describe how bad. I felt deflated and just very alone even though I was sitting there with [my husband] I felt very alone. (R3,19,6)

Yet for several reasons, shock and pain are not always a mother's strongest reactions. For Joni, finding a specific diagnosis was insignificant compared to the fact that Valerie was doing well at that moment. She received an official diagnosis from the National Institute of Health after a year of concerns about Valerie's failure to thrive, feeding difficulties, and

three life-threatening surgeries. Joni put the day-to-day realities into perspective

My husband is reading a long list of symptoms [relative to the diagnosis]. And I'm wrestling with this little child that's doing very well. I'm playing with her and I couldn't care less what the paper said. My baby wasn't dying. And I said, "look at her. Do you think she cares?" And so we have no limitations (J1,20,4). So they hand me a piece of paper that tells me what her future was going to be—what do I care? She may not be alive tomorrow; we have made it through a month of horror [surgeries]. I'm sorry, my kid is now laughing and playing with me, and I don't care what that paper is. (J2,7,12)

Even though this was Joni's reaction at the time of diagnosis, she had already gone through months of agonizing, wondering what could possibly be wrong with her daughter. So despite the severity of Valerie's prognosis, there was a level of relief in knowing they would no longer have to search to find answers. Tomi also experienced a level of relief when doctors' medical findings supported her premonitions. She had spent months seeking answers for Daniel's chronic illnesses. Receiving even a partial diagnosis validated her suspicions that she had known something was wrong with her child

The GI [gastro-intestinal] group found some lower esophageal weakness. That's the first time that I started to get the picture that Daniel had low tone generalized. And yes, that he did have some delays, and yes, he would need a developmental assessment. (T1,12,16)

The situation was different for Suni, who at the end of the study continued to have ongoing anxieties that they had no specific diagnosis for April. She explained that her "search would continue" (S3,20,5).

Finding a diagnosis appeared to be a turning point for many of these mothers. For some, the diagnoses were unexpected and emotionally wrenching. For others, being able to have a diagnosis to an obvious problem provided a level of relief. And for one mother, the lack of a specific diagnosis continues to deny her the possibility to fully adjust to her daughter's developmental delays. When I asked them to reflect on the time of diagnosis, some of the mothers expressed concerns for the manner in which their children's diagnoses were delivered.

Often the interaction with the professional who delivers a diagnosis of disability is the first professional encounter for families embarking on a long journey with disability. Three of the 6 mothers, Boni, Lori, and Roni expressed concerns for the way professionals delivered their children's diagnoses. The other 3 mothers, Tomi, Joni, and Suni, expressed no specific concerns for the manner in which the diagnosis was delivered.

Boni and Lori received diagnoses shortly after their children's birth. Neither of them had anticipated receiving any kind of a diagnosis. For Lori, the diagnosis was delivered shortly after Megan's birth, when her husband went to the nurses' station to ask why the baby hadn't been brought in to them and a nurse said, "we think your baby has Down syndrome" (L1, 2,17).

Yeah, it was at the nurses' station too, you know, it wasn't even like they pulled him in and said, "come here, sit down, we need to tell you something." It was just over the desk at the nurses' station, they

said, "we think your baby has Dawn syndrome, so we will be in there to see you guys in a minute." (L1,2,21)

Lari described further insensitivity of the medical personnel

One doctor actually came in and said to me, "you can't have to take this baby home you know." He knew that we didn't know [of our baby's disabilities] until we had had her; so he didn't think it was fair that the choice [of abortion had been] taken away from us. He didn't think that it was right that we didn't have the choice to make whether or not we wanted a handicapped baby, so he was just letting us know that we didn't have to take the baby home, [we could give her up for adoption]. (L1,3,4)

Bani explained her reaction to being told that Derek had Dawn syndrome

In my opinion, the whole thing was handled inappropriately. [My husband and I] both heard the news from nurses, and those [comments] were [only] suspicions. And he didn't have all the signs [of Dawn syndrome] - he didn't have simian crease, his fingers were somewhat short, but not completely. He did have the fold in his neck. But even his features now are not extremely Downs. So they had only suspicions. Not exactly appropriate in my opinion. (B1,21,11)

In contrast, Rani waited approximately 8 weeks from the time the geneticist was called in to consult with them before the official diagnosis was given. During the diagnosis delay she had reconciled herself to the coming news that Steven would have developmental delays. When the geneticist delivered the official diagnosis Rani had to confront the full reality of her son's special needs and the cold factual way in which it was delivered

[The diagnosis] was just very factual, and there wasn't any type of counseling or any type of—it was just kind of, 'here it is, like it or lump it'. I think [the geneticist] is a very knowledgeable man, but his presentation—it was pretty heart rendering. I had a horrific time

with it. Just the way it was presented, it was very matter-of-fact.
(R2,2,11)

Rani described the scene further

I mean you are just there [with the geneticist], and [since it is a teaching hospital] there are these residents, and they tell you, "this is what we think it is" and then they just left and we just feel devoid (R3,19,4). I just think that same discretion needs to be used as far as who is in the room, how the whole thing is presented . . . There were a lot of things that [the geneticist] said for the sake of learning. I just remember it being a very awkward situation. (R2,4,1)

These 3 mothers expressed shock in receiving the diagnoses. In contrast, Tami, Jani, and Suni did not express concerns for the manner in which their children's diagnoses were delivered. Rather, they each appeared to experience some relief from finally receiving a diagnosis. Both Tami and Jani's concerns were primarily regarding their children's current health status. During Jani's search for a diagnosis, she had seen Valerie undergo multiple surgical procedures. She felt some relief that Valerie would be subjected to no further tests to determine a diagnosis. Tami had sought diagnostic information from numerous medical professionals in an attempt to have her suspicions validated. However, Tami felt a great deal of concern that the diagnosis was incomplete and might have only been a partial reflection of what Daniel's problems would be. Suni too still faced some uncertainty as to what April's diagnosis of "global developmental delay" would mean in the future. The relief these mothers felt in finally receiving diagnoses may have pre-empted any concerns they had regarding the manner in which the diagnoses were

delivered. Yet once the diagnoses were delivered, each of the six mothers was faced with the implications of that diagnosis.

Coping with the Diagnosis

The 6 mothers in the study employed a variety of coping strategies in an attempt to come to terms with their children's diagnoses of delay or disability. The following are descriptions of coping strategies the mothers used.

Palliative coping. Thompson, Zenman, Fanurik, and Sirotkin-Roses (1992) identify palliative coping strategies as emotion-focused and to include denying, questioning, and wishful thinking. These strategies may result in a temporary reduction of stress, but do not increase the individual's ability to cope with ongoing stressors. Roni reacted at first by denying the circumstances or wishing the diagnosis would go away. She justified her use of palliative coping strategies as, "It's a healing process for the parents too, in a lot of ways, and at least it was for me. It bought me a little time" (R2,6,20).

At the time of initial diagnosis of disability or disease, families often deny the circumstances in which they find themselves. Tomi reported, "I don't know if you can call it denial if you know you are in denial, but we just redefine normal every month or so to fit Daniel" (T1,1,14). She continued

Sometimes you just have to pretend like nothing is happening to get through it. I remember one time [my husband] was in denial, and I

remember telling him one day, just sitting down to have a conversation and saying, "I need you to come out of your denial for just 10 minutes so that we can make this decision and figure out what is going on. You can stay in your denial the rest of the time, because really I like escaping into your denial every now and then [myself]" (she laughs). It was to be that aware that someone was in denial, for him to actually say, "okay" and come out of his denial for 10 minute periods of time and slip back in. But definitely I knew that [there were times when I was chasing to] escape into his denial. (T4,34,15)

Rani's use of denial manifested in a different way, "Things are just a little foggy for me there as far as exactly the bits and pieces, I think my brain just kind of blacks it out" (R1,22,18). She elaborated, "At the time initially, I was a little bit overwhelmed, and in denial" (R2,6,13), and "I was just having a hard time coming to grips with it all" (R2,10,14). Lari agreed, "It is just this mind frame like, 'my baby is not going to be retarded, and my baby is not going to be delayed'" (L1,11,12).

Although Suni felt a level of understanding regarding April's delays and diagnosis, her husband had difficulty

At first my husband didn't seem to want to believe that there was anything wrong with April. He just kept saying that was the way she was going to be, that it was her. But he is getting more accepting of it. He did go with me to all of the evaluations and all of that. But I think he just thinks right now that given a little time she will be fine, that this won't be something we have to worry about past preschool. (S1,23,6)

Suni's concern for her husband's denial emphasizes one of the risks of this coping strategy, which is that denying the existence of a problem may also eliminate the search for possible solutions.

A second palliative coping strategy is questioning "why" one is having these experiences. These mothers sought meaning for their experiences and were thus looking for explanatory causes. Some looked to God, others to genetics, and others to their own behavior or misbehavior. Joni expressed, "I look at God and I say, 'Why? How can You do this to a child?'" (J2,11,7). Roni said, "I think any parent kind of wonders 'why?' if things happen to a child or your family member, you tend to question as to 'why?'" (R3,2,4). "As a mom I think, 'what have I done? What could I have done differently?'" (R3,13,4). Suni's explanation of her search to find out "why" expounds from her coming to terms with April's diagnosis to future implications for her family and directions for April's therapies

We're still searching to find out 'why' (S1,19,9). Our next step is maybe genetic testing or something like that. I don't know if we are going to have another child or not, but if we were going to have another one, for sure we would definitely do that (S2,3,7). Not knowing is hard, not knowing why this happened. And I wonder if we knew if there would be new things that we know we should work on. But we don't know why. So that is hard. (S2,13,19)

Mothers who become "stuck" in seeking for a reason behind the diagnoses may expend valuable energies which, when explanations are not forthcoming, rob them of direction in finding solutions to current problems.

A third reported palliative coping strategy mothers used was wishful thinking. Jani indicated, "I can't stop hoping" [for a cure] (J2,5,3).

Because of same ambiguity regarding Steven's diagnosis, Rani related

I think I was just kind of hoping because the things we were finding out were a little vague as far as it may or may not be this syndrome, the DNA did not confirm it. So in your mind there is always that little shred of "well, maybe it's not—maybe he will overcome these delays." And my mind held on to that (R2,6,15). With a syndrome, you get sheets that say, here is what to look for . . . I guess at the time you just say, "Yes, but he'll be able to do this." They don't know from every child's point how profoundly they will be affected. (R3,9,6)

Bani explained that the uncertainty of the future also caused her to be wishful

I like to get things resolved. I think the hardest thing for us is not knowing how Derek is going to turn out. Is he going to be mild, be moderate, be severe . . . It's not that I want the situation to go away, but the uncertainty about it [is difficult]. I don't like uncertainty. We all wish we had a crystal ball, and I know I can't do anything about it. (B3,3,10)

Mothers may also run the risk of becoming "stuck" with this strategy—failing to realistically confront the day-to-day issues of raising their children.

Although these three palliative coping strategies were not reported by all of the participants, each mother's story included at least one palliative coping strategy. One advantage of palliative coping strategies may be that they allow the person time to assess and adjust to the realities of their new situation. This time cushion enables the mothers to gather the support they will need to fashion more effective and long-lasting coping strategies. The risk in using these strategies is "getting stuck"

and persisting in using them rather than moving to more effective strategies. For the mothers in this study, such strategies were short lived, however, and eventually gave way to more permanent adaptive coping strategies.

Adaptive coping. Adaptive coping strategies include reframing, searching for information, and turning to religion (Thompson, Zeman, Fanurik, & Siratkin-Roses, 1999). Parents construct adaptive coping responses when they finally realize that their children face a lifetime of medical and developmental problems.

Adaptive coping often begins with reframing the problem at hand. Turnbull and Turnbull (2001) define reframing as, "changing the way one thinks about a situation in order to emphasize positive rather than negative aspects" (p.47). As the 6 mothers confronted the full reality of their children's conditions, they struggled not only to understand, but also to adjust to these realities. That process required that each of the mothers reframe the reality before her. In addressing the overall adjustment to Steven's condition, Rani stated

It is almost like you put aside the ideas and the cognitions of what you recall of the child you had in your mind, that you were going to have, and you embrace the new child Because you really see wonderful things about a child, even though it wasn't quite what you had planned. (R1,21,8)

As Rani recalled the progression Steven made while receiving therapies, her retrospection allowed for a further example of reframing

I'm fortunate compared to many of the parents, it's almost like a downward comparison, and I don't mean to do that. But it's almost like a natural human thing we do to help ourselves in some way, coping with it all. But you kind of look around you see, and gosh—how would I cope if I had a child who couldn't even communicate with me in any way, or pick up a toy, or anything. (R1,20,5)

Parenting Megan was Lori's first experience as a mother. Her explanation of how she felt about Megan's delayed development was another clear example of reframing

We didn't really know what to expect about a baby anyway, so everything that she does for us is normal. Parents are just saying that their kids grow up so fast, and I'm like, "mine is taking her time" . . . We think we will need a parent group if we have a normal baby [laughs] because this is all we know—this is normal. This is just the way it is. (L1,4,3)

Joni provided an apt metaphor for the reframing experience of these mothers as she explained her feelings of watching Valerie's progress in therapy

We just get so excited about good things. We can just find positives in all kinds of things . . . I think what happens, you have a lot of pain, and you take that pain and you twist it; and it somehow becomes growth. And that promise would never be there, that progress would never be there if you didn't have the pain to twist. You may have other pleasures, you may have other wonderful things happen; but that particular promise would not be there were it not for the pain that you twisted or the lemons you turned into lemonade. (J3,8,9)

Rani, Lori, and Joni's examples are representative of all 6 mothers. These women sought to see positive aspects surrounding their children's disabilities.

A second adaptive coping strategy is seeking information. The adage "information is power" certainly held true for these mothers. Following their children's diagnoses, all 6 mothers used this adaptive coping strategy by actively researching to become more informed regarding specific diagnoses, possible therapies, and general disability information. For Lori, information on Down syndrome came from multiple sources. She explained, "I didn't understand at all. It was probably my mom [a nurse] who talked to me most about it . . . As we went on talking to different professionals we got more information" (L1,4,17). And later, "Whenever the Down Syndrome Association finds out that there has been a baby born, they usually send information—we got information from them" (L1,13,6).

Information did not come so readily to Tami. After Daniel received his diagnosis of "benign external hydrocephalus," Tami researched and found no such diagnosis (T2,9,3). Frustrated, she returned to the professionals and asked for something in writing on the diagnosis. Eventually she had success

I went to the Hydrocephalus Foundation and found a pediatric neurosurgeon who would call me and speak with me. He had heard of the term and he had written a book and there was a chapter on it. So he sent me the chapter. I [found this foundation] over the Internet . . . He was the one who had founded the Hydrocephalus Foundation, so he was into what he was doing. (T2,9,19)

Rani and Joni, both mothers of children with rare metabolic syndromes, also found a lot of information over the Internet. Because of the rarity of Steven's syndrome, Rani reported that "even what [the doctors] had found was online" (R2,2,4). In the nearly three years since Steven was diagnosed, Rani observed a difference in what was available, not just about the diagnosis, but also suggestions for therapies

There is a wealth more now on the web. There are actually web pages dedicated mainly to the children . . . You see all the different interventions, which helps me because I learn about what some parents have done that has worked. There is quite a bit of information, way more now than there used to be. (R2,7,7)

Jani told how the geneticist who diagnosed Valerie "came out with the same stuff we had found from the Internet" (J1,19,6). Joni joined a list serve of families who have children with the syndrome and received a lot of support and information from that source and from a foundation for the syndrome (J1,21,2).

Donna H, who is head of the . . . foundation, she put us in touch with NIH [National Institute of Health] and NIH flew us up north and the information we got from them was just absolutely wonderful . . . They were the ones who kind of completed the information. (J2,10,15)

Individual research was important for Suni in understanding sensory integration, one aspect of April's delays. Suni reported

I read the book and a lot of it did pertain to her" (S1,176,9). [But there was still] more and more researching and asking questions [to do]. People hand you stuff here and there, so I'm glad that I'm a go-getter. Some people, if they don't know what to ask, they don't get as much information. (S2,2,8)

Boni and her husband combined the expertise of their pediatrician with individual research

Some of the medical, what we were dealing with, Dr. W [our pediatrician] knew a lot of it. But [my husband] is a good researcher, so he put a lot of it together. We then passed that information on to our pediatrician. [Our pediatrician] is very proactive. (B1,8,6)

Clearly these mothers felt empowered by the information they gleaned about their children's diagnoses and possible therapies.

All 6 of the mothers reported utilizing the adaptive coping strategy of turning to religion. Turnbull and Turnbull (2001) define this strategy as "deriving comfort and guidance from one's spiritual beliefs" (p. 47). The manner of support that these mothers found from religion varied. The first form of support came from congregations. Joni explained, "the people of the church were supportive and shared my concerns" (J2,5,1). Further evidence of this connection with a church family was found in her statement describing the ordeal of Valerie's surgeries. "I called the church people. They came; they took [my other child] home with them. I called another church family, and they sat with us" (J1,10,10). Suni also found comfort through her congregation; yet April's special needs raised a further obstacle relative to the family's spiritual values and desire to connect with their church

One of the things I was kind of upset about, my older daughter went to a wonderful preschool, a Christian preschool. They love the kids and she loves learning about Jesus. So I think that is just wonderful. And I'm like, April is going to kind of miss out on that

because she is not going to that school. We can get her in Sunday School and other things, but yet, she needs to be in intervention where she needs to work on other things right now. You just have to weigh things as they come along. (\$2,16,9)

A second manner of turning to religion is evidenced by a personal relationship with a higher power. Boni acknowledged, "My faith is stronger in God . . . Religion has always been in my background, but I'm not what you'd consider a religious person. It's my private faith. It has just reinforced my belief, making it stronger" (B3,9,19). Lori felt it was an honor placed upon her by God to be allowed to raise a child with a disability. Her relationship with a higher power assisted her in coming to terms with Megan's diagnosis. She extended the comfort she received from her religious beliefs to her husband to assist him in his acceptance of Megan's diagnosis of Down syndrome. Lori explained

I am very religious and [my husband] is probably less so. I just told him it was what God wanted . . . God wanted us to take care of her . . . I told him I felt honored that God felt I was good enough to take care of her the way she is. (L1,29,6)

Roni derived great comfort from her relationship with a higher power. She reflected upon the religious perspectives she had experienced over the nearly 3 years since Steven's birth

I try to trust [God] as much as I can. When there is a situation like with Steven . . . you tend to question as to why. But I think it made me turn closer to God. We just have to believe that He chose Steven and Steven chose us for a reason. And whatever that reason is, I feel like God has a purpose through Steven. We pray for His will, whatever He chooses. We want Him, obviously, to keep Steven with us. But if He doesn't choose that, we pray that He gives

us strength for whatever . . . I feel God's hand in this and I just know that only good things are from God and He is in control. (R3,2,1)

Tami explained her day-to-day reliance upon God to assist her in coping with the stressors of Daniel's chronic illnesses

First of all, without God, I am nothing. I am weak . . . With God, there is nothing I can't do. So that is my attitude and now that I have God on my side, I know that I can do anything. So guess what, Daniel is easy. If I didn't have God, this would be impossible to do. And I had God when Daniel was born, so yes, my road has been much easier because that has just been a basic foundation for anything I have ever done. (T5,18,20)

She elaborated upon specific experiences where she felt her faith had been strengthened as she turned to her higher power through prayer seeking the copacity to mother Daniel in a kind and loving way

I pray a lot. I pray, and like from the very big to the very little. There were times with Daniel screaming where, you know, I don't normally pray for things. Like my prayers are usually for strength or to keep loving or keep doing or not to get hardened . . . I don't ever pray for Daniel being normal or anything like that . . . But there were times when I prayed for me not to hurt that child. And that is probably the only time when I prayed for a concrete thing, "just don't let me hurt this child." And I just put him down, and I tell you, I can think of maybe four times in the whole 2 years when it was so rough with Daniel. Two years when there were many nights that I hadn't slept for a long time, and he was just screaming and I couldn't console him. I knew he was either in pain or something was wrong with him and I couldn't fix it. [I was] feeling totally incapable and it was at this point when you don't know what to do anymore. And I would pray, and all four, maybe five times in 2 years, that baby stopped crying. I mean all of a sudden. So I didn't want to use it too much and jinx it [laughs]. I knew it worked . . . Yeah, prayer has been there for many, many answers. (T5,23,8)

Dealing With the Implications of the Diagnosis

The specific implications of the children's long-term diagnoses, especially as they were related to a prognosis, make different demands on the mothers' coping processes. Complex, life-threatening medical problems compounded the issue of disability for both Joni and Rani. Both of these mothers appeared to have a premonition of the effects of their child's diagnoses on the future of the family. Joni described her family's future

I think her daddy's biggest loss was he thought the kids would leave home some day and we would be able to travel. But it looks like we will have a companion for life . . . I don't know; there are advantages and disadvantages. When she is suffering, it's not good. There is that, and that you need a lot of financial support. We don't know how long she will live, I guess we can think of it as a blessing that she will most likely not make it to age 30, because that is probably about how long I can hang in there. I don't have to worry about her being abused after I'm gone, because I just don't trust the Medicare system. (J2,8,19)

Rani also expressed concerns for her whole family's future

I worry mostly about his future as far as when I eventually get to the point when I get older and what will become of him if he can't take care of himself independently. I don't want the whole group home situation, just with all the mistreatment of folks, elderly and everything. I know, what a responsibility for me to put on his older brother. I am always saying, now if Steven, when he gets older, if he can't take care of himself [and his 5-year-old brother says] "well, I'll take care of him Mommy." I can't look for a commitment that early, but you just kind of always want to instill that he is his brother's keeper and just want to make sure that he is cared for. (R2,11,8)

Of the 6 mothers, Suni's participation in the study was most recent from the time she received her child's diagnosis. Her daughter April's

diagnosis of "global developmental delays" was also the least specific of that faced by these mothers. While each of the other mothers in the study were able to name the condition that led to her child's developmental delays, Suni's coping involved a continual search for answers to the question of etiology. This also had implications as she thought about April's future

I guess I worry in the long run about her future. That is the stressful part, not the everyday things. But the future and worrying about the future for her is the biggest stress. I don't want her to be a kid that is made fun of. Now it's not a problem—kids are really pretty protective and nice. But when they get to school and say this or say that. But yeah I think the future is more stressful than the present. (S2,13,4)

Tami's coping with Daniel's diagnosis, therapies, and transition to school-based services was closely related to her acceptance of him as an individual

To us, Daniel is perfectly normal, and it's the rest of the world that causes us problems [laughs]. It's nothing anymore; it's the doctors and the school system. Because the level of normalcy that we want in his life, if we are to deny that that is what is happening, it is to deny Daniel. And he is Daniel. He does certain things that only Daniel does. (T4,35,11)

These mothers felt a level of anxiety as they anticipated new challenges. Rani explained, "It's kind of a constant knowledge in the back of your mind that things are coming up. It's just a constant set of, one thing we know, and after that is over, then another thing presents itself" (R4,10,18).

While anticipating further challenges, the mothers recognized the growth they had made through the diagnostic process. Rani explained

I have come a little bit further now . . . It's still hard for me, I won't deny, and I would never judge other parents who have to deal with any diagnosis. Some get it together immediately, and some take healing time, and some never get it together. (R2,11,3)

Lari summed up the distinctly personal aspect of the process

There were a lot of people who could have [provided support], but it wouldn't have done anything for me. It wouldn't have made me feel better—it wouldn't have taken away the pain. It wouldn't have done anything. It was just my own to deal with. (L2,11,2)

Summary of Becoming Aware: Something is Very Wrong

For the mothers in this study, becoming aware that something was very wrong with their child was a very individual experience. In this first significant sub-stage the mothers experienced suspicion that something was wrong, though in some cases these suspicions were first raised by medical professionals and in other cases months passed before suspicions arose. The mothers received different levels of response from medical professionals to their suspicions, and at the time this study ended one mother still had not been given a complete diagnosis of her child's disabilities or a complete prognosis. Each mother's emotional reaction to hearing the initial diagnosis seemed to depend upon whether or not she had previously suspected there was a problem. Each mother used different combinations of palliative coping techniques, yet all used a combination of three adaptive coping techniques: reframing, searching for information, and turning to religion. Their coping processes varied the most when it came to how they dealt with the implication of their

children's different diagnoses. However, every mother expressed her belief that she had grown in her ability to cope with her child's special needs.

The varying nature of these timelines of diagnosis and treatment supports my premise that facing the realities of a child's disability is not a linear process that everyone moves through the same way. Despite where these mothers found themselves in the process of dealing with their child's diagnosis of delay or disability, once the diagnoses were received all sought developmental early intervention services for their children. In the following chapter, I report the mother's challenges in obtaining and enrolling their children in developmental services.

CHAPTER 5 FINDINGS PART 2: PARTICIPATION IN EARLY INTERVENTION SERVICES

Introduction

In this and the previous chapter, I address the five stages that mothers described experiencing as they came to terms with caring for their children with developmental challenges. In chapter 4, I detailed the challenges these mothers faced during the diagnostic stage, *Becoming Aware: Something is Very Wrong*. In this chapter, I report on the stages involved with the mothers' participation in early intervention program services. These stages include: (a) Discovering, Seeking, and Finding Services: Awareness of Early Intervention; (b) Enrolling in Services: Access to Early Intervention; (c) Learning the System: Reception of Services; and (d) Looking Back: Suggestions for Improvement of Early Intervention. As was mentioned in chapter 4, the services available to these mothers were part of the Program for Infants and Toddlers with Disabilities (Part C of IDEA). In order for a state to participate in the program, it agrees to ensure that early intervention will be available to every child and family no later than 45 days from the time of referral.

Bronfenbrenner's (1979) social ecology theory categorizes the different microsystems, or environments, in which a family participates. By

enrolling in Early Intervention services, these mothers added one or more microsystems to their family ecology. The mesosystemic connections, or the interrelationships and interactions among two or more settings in which these mothers participated, were of particular interest in this study. Of note was the quality of these interactions.

Here I report the obstacles mothers overcome as they discovered, assessed and received services. During interviews, the mothers identified and explained the attitudes, skills, and methods they valued in service providers and service provider strategies. In addition to discussing the four stages following diagnosis, in this chapter I discuss providers' interactions with parents and children, as well as follow-up interviews with those service providers.

Discovering, Seeking, and Finding Services: Awareness of Early Intervention

Of the 6 mothers in this study, 5 had children with established conditions, i.e., Down syndrome, Rubinstein-Taybi syndrome, hydrocephalus, Carbohydrate-Deficient Glycoprotein syndrome. Typically, in cases like these, medical personnel should provide parents with an immediate referral for early intervention services under the federal Early Intervention Program. Yet only 1 mother, Lori, was referred to the program at the time of diagnosis. The other mothers were not informed of the availability of developmental services. In this section, I detail the ways the mothers discovered available services.

At some point after realizing their children had genetic, health, or developmental concerns, the mothers in this study began to recognize that their children not only needed medical services, but also needed developmental services. They saw the early signs of developmental delays in their children. They suspected that there was more going on than just a medical condition; their children were not meeting the expected early childhood milestones. Lori received information about the local early intervention program before going home from the hospital. She was the only 1 of the 6 participants referred immediately to early intervention services. Lori described the process she encountered

Once a Downs baby is born, they start making a lot of referrals from the hospital because they know that you're not going to know what you're doing when you leave with that baby. So they make a referral right out of the hospital for your early intervention. (L1,16,9)

Lori speculated that multiple services and supports were going to be required for her daughter. She experienced how early intervention services should function in local communities. Lori's physicians were clearly knowledgeable of the early intervention system and put Lori in touch with them before leaving the hospital.

Although Boni's son Derek also had a diagnosis of Down syndrome, her process for accessing services was not as direct

Our pediatrician was able to get me in contact with other mothers who had children quite a bit older than Derek that had gone through some of this. That got me pointed in the right direction for intervention. They are the ones who kind of explained it better. [My pediatrician] was the one who got me in contact with other

parents. I think he felt that they knew how to do this—how to get me in touch with the other things I needed to do. I'm not sure that he was as familiar [with the early intervention program]. (B1,7,8)

Boni was able to make the necessary contacts to have Derek evaluated for early intervention services by contacting other mothers who had children with Down syndrome. However, it was left up to Boni to initiate the contact with the other mothers. By not referring Boni directly to early intervention, the physicians at the hospital did not provide Boni a direct route to services. Boni was left to search for programs by indirect routes (e.g., other mothers). Fortunately, she did take the initiative to call other mothers for more information.

Receiving information and a referral to early intervention programs was even more difficult for the other 4 mothers in my study. After his diagnosis of Rubinstein-Taybi syndrome, Rani's concerns for Steven's ongoing development were manifest during her visits with the pediatrician who noted the milestones that Steven was not accomplishing, but did not refer Rani to the early intervention program. Only after Rani pressed the physician to recommend something to them (as Steven approached 6-months of age) was the feasibility of early intervention services considered as an option.

Tami suspected that Daniel had developmental delays and would benefit from an expert to assess his development. She explained

He was not sitting up, not doing any belly stuff at all, won't tolerate any belly time whatsoever. Just started holding his head up at like

five months, isn't babbling, doesn't even seem to be hearing most of what is going on. He'll sleep through anything. (T1,13,2)

Despite Tami's ongoing concerns and constant consultation with her physician regarding her son's status, she was not referred to the early intervention program. As a nurse, she knew that his development was lagging; yet she was unable to convince medical professionals of the need for interventions. Only when she inadvertently became aware of a regional early intervention program through the social workers at the John Tracy Clinic at the time of Daniel's release from those services and doggedly pursued that avenue was Daniel able to access a developmental assessment.

For Jani, discovering that services were available for her daughter was also frustrating. Although Valerie had been ill since birth, Jani did not receive information about developmental services until Valerie was approaching 1 year of age. She explained, "I knew there was something wrong with my baby, she wasn't progressing" (J2, 18,16). Medical professionals did not make early referrals for development services in spite of Valerie's medical condition and Jani's suspicions that Valerie was delayed in acquiring cognitive, motor, and communication milestones during her first year.

Based upon the diagnoses of these children, 5 of the mothers should have had referrals to early intervention program services immediately following the diagnoses. Yet, 4 of the 5 mothers left the

hospital without any referrals, much less an Individualized Family Service Plan (IFSP). This lack of information regarding access to developmental services for their children contributed to the stress these mothers experienced.

Suni's situation differed from the other 5 mothers in that April did not have a medical diagnosis. However after confiding concerns about April with a close friend in another state, that friend helped Suni realize that April might need developmental services. Yet even after expressing her concerns to her pediatrician, Suni was advised to wait a few more months to see if April's development would catch up.

The experience of these 5 mothers suggests that medical professionals may be reluctant to make referrals to developmental professionals. Concerns for their children's delayed development, however, prompted these mothers to seek developmental services on their own despite lack of support from medical providers. Although devastated by Steven's diagnosis, Rani described a conversation with Steven's pediatrician regarding accessing developmental services, "I said, 'let's not wait and catch this later. Let's start young. I don't want to wait until he reaches a year or 2 years and we know we have . . . wasted time for him'" (R1,17,8). Lori had the advantage of her mother's nursing experience as a resource to supplement what her doctor told her. Her mother advised her to seek the services of a physical therapist and an

occupational therapist. Similarly, Tami's and Joni's nursing experience gave them a supplemental knowledge about possible services to assist their children. Suni benefited from ongoing communication with her friend whose daughter was in an early intervention program as well as her own experience as a recreational therapist serving individuals with developmental disabilities. Besides the contact with other mothers of children with Down syndrome, Boni worked with a woman whose child had autism and who had benefited from early intervention services. But all these means of accessing supplemental knowledge about available services were circumstantial. These mothers were driven to find help and sought information on developmental services in any manner they could.

Summary of Discovering Available Services

In general, the first step for mothers of children with disabilities is acknowledging that they need services. All 6 of the mothers in my study came to terms with this fairly quickly. Acknowledging the need for services was a vital step towards enrolling their children in developmental services. However, acknowledging that there was a need was not sufficient for the mothers in this study. They needed specific information and contacts in order to directly access services. In the next step of finding these services mothers should have been assisted by medical personnel and in 5 of 6 cases, however, they were not. The reason why physicians do not make direct referrals for early intervention services

clearly warrants further investigation. Although 5 of the 6 mothers in my study had medical diagnoses for their children, challenges in accessing early intervention services were still ahead of them.

Enrolling in Services: Access to Early Intervention

Even with their hard-won awareness that developmental services may be available, accessing services was not easy for these mothers. Due to the tremendous developmental changes that infants undergo in a short period of time, the federal Early Intervention Program prescribes that following a referral, the child should be assessed, and if found eligible, an IFSP written within 45 days of referral. Because of the difficulty most of the 6 mothers faced in making contact with the early intervention program, unnecessary time was wasted before their children were enrolled in services.

Rani expressed the confusion that many parents face when confronted with a child's developmental needs saying she was "lost about" where to start. She had "heard of physical and occupational therapy" but didn't know how to contact them or what they could do for her child. "You don't think of occupational therapy for a child" (R1,18,12). Lori concurred, "Until you need it, you really have no clue that there are all these people out there to help you" (L1,12,17). Thus, it was important for these mothers to discover the multiple facets of the early intervention

system including what early intervention program services could offer their children and what specific services their children needed.

In addition to the fact that medical personnel did not refer these mothers to early intervention services, bureaucratic delays due to local early intervention program policies may also contribute to parental frustration. Tami discovered two sources where Daniel might receive a developmental evaluation, the local early intervention center funded through the federal grant and a private developmental center that accepted insurance. Anxious to get Daniel into services, she applied to the two programs simultaneously. She explained, "It was like a race, let's do insurance, let's do state, and let's see who wins, because I want something going now" (T2,3,9). Weeks later, frustrated over the lack of progress being made toward having Daniel evaluated she gained an opportunity to directly contact those in power.

I went to an information fair for kids with developmental problems sponsored by Regional Early Intervention Center . . . I actually found the people who I had been referred to. So I approached each and every director of the place I had been referred [to] and said, "What is the problem? You know, 4 weeks ago I was sent a letter that you got the referral, I still am not scheduled, and you don't return my calls." It was like face to face, it was perfect timing. And within 2 or 3 days I was getting calls and Daniel was into the program. (T2,5,5)

Likewise, 3 of the other mothers also experienced frustration in scheduling evaluations for developmental services. Suni was told that they didn't have an opening for her child and that it would be several

months before she would get services. This was in direct violation of federal law, which requires no more than 45 days to get an evaluation and to commence services following referral. Boni explained the process she went through to schedule Derek's initial evaluation

I called, and the way I understood it was that [from] the day I called, they had 45 days to evaluate my son. They told me it would be after the first of January that the evaluation would be done, and I had called them in September. So this was not acceptable. I work for [a large regional medical facility] and I...contacted a few people through there to get us a sooner appointment (B1,12,5). I hate doing those things, but this is my son. And that is the only way I could talk them into it. They had 45 days to do this and we forced the issue. This is my child, and 6 months makes a huge difference. (B1,13,1)

Joni also experienced difficulties in accessing specific services

I wish I could get things to move faster. I tried to get speech therapy for over a year, and we had it for a while, but in trying to get it started up [again], I haven't had any response. When we started out, months went by before I had anything. And to have options available. If one therapist doesn't work out, if there is a personality problem between the child and the therapist, or the parent and the therapist, or if there is a problem with the environment that the therapist wanted to work in, there would be some options. It's just one of those things you have to be concerned about. (J3,9,5)

The unnecessary frustrations these mothers experienced in accessing early intervention services robbed them of time and internal resources that could have been spent in caring for their families.

Summary of Accessing Services

Clearly, knowing about the early intervention program and making the appropriate referrals to the program should have been sufficient to set

up services for the children within the 45 days specified by federal regulations. However, the mothers in this study experienced significant obstacles and delays to accessing developmental services for their children.

The 6 mothers were discouraged with the difficulty of seeking and accessing early intervention program services. Lack of personnel and resources to serve infants and toddlers were systemic problems in most of the early intervention programs. As shown by the concerns raised by these mothers, secondary delays in procuring services for their children existed even after they finally received referrals. Additional bureaucratic problems arose once children started receiving services. Mothers then had to learn how to maneuver through the delivery system.

Learning the System: Delivery of Services

Living with a child with developmental disabilities often becomes even more complex once the child is enrolled in developmental services. Issues such as multifaceted legal requirements, third-party billing, and formats for service delivery are often confusing for families. When the original IFSP is written, the service coordinator should give the family detailed information about how the program works. Early intervention program service coordination is a mandated service under Part C of IDEA. Service coordination is defined as an active, ongoing process that assists and enables families to access services and assures their rights and

procedural safeguards (Early Intervention Program, 1999). For instance, before each formal meeting to establish a plan of service (IFSP), parents must be informed of their legal rights. The service coordinator should also explain to the family their options for choosing a specific model of service delivery. Yet, despite the provision of service coordination, many parents find they only begin to understand the complexities of the early intervention program by the time their children transition to school-based services at age 3. In this section, I illustrate several common challenges inherent in the early intervention program that these mothers had to learn how to negotiate. They include (a) navigating among service delivery models, (b) establishing relationships with service providers, (c) establishing new relationships due staff relocating or taking temporary leave, and (d) transitioning to preschool services.

Navigating Among Service Delivery Models

There has been increasing emphasis to provide early intervention services in "natural environments" in the 5 years since the 1997 amendments to IDEA. Natural environments are those environments in which an infant or toddler would participate if they did not have a disability (e.g., the home or childcare facilities with typically developing peers). The environment of choice for these young children is typically the home. However, services are not always available to families in their homes and continue to frequently be fragmented among multiple service

providers in multiple locations. Each different provider and location adds another microsystem with inherent challenges of personalities and logistics. Mothers are frequently required to juggle their schedules as they transport children to receive services. Additionally, when children are placed in intervention centers for services, mothers often face the guilt of sending their very young children away to school.

At the time of the study, the 6 mothers faced a variety of service delivery packages. Rani's son Steven and Suni's daughter April both received all of their services at a local early intervention center. Suni had requested that April's related services (speech-language therapy and occupational therapy) be provided either at the beginning or end of the school day so that she could participate in these therapies while dropping April off or picking her up from the center. Lori's daughter Megan was also enrolled at the early intervention center and received related services there. However, Lori continued to take Megan to additional private practice speech and physical therapy since these services could be scheduled at times when Lori could participate in the therapies.

Although each of the 6 mothers' children initially received same services in their homes, it was also necessary to transport their children to some of the therapies. This situation presented two significant challenges. The first was multiple and fragmented visits to therapies. Both Tomi and Rani reported occasionally going to medical and developmental

appointments as often as 6 to 8 times in a week. Second, the problems of frequent therapies were compounded for some mothers by the distance required to transport children to therapies. After moving to Florida, Tami lived in a rural area and transported her son approximately 30 minutes each way to and from therapies. She described a typical intervention day

Tuesdays we will see [the home interventionist] in the morning for early intervention. As soon as she leaves at 10:00, we [drive in to the therapist's office where] at 11:00 we do speech. Then I'll feed him, usually in the parking lot or the park there, and then take him over at 1:00 for physical therapy. By the time we arrive home at 2:30 or 3:00 we're both exhausted. (T3,8,18)

Jani lived an hour from the early intervention center where speech and occupational therapy services were provided for Valerie. She attempted to have additional services provided in her home so she wouldn't spend 2 hours driving back and forth. She explained her dilemma

I would have gone local, I just really didn't have a choice . . . there was no one local to go to. I even offered to go to the schools, I called places, and there was just nothing available to us in this rural area . . . We could always drive in and drive back, but by the time you get a child dressed and loaded in the van . . . you have to allow for that plus parking time and walking in and getting there, you've driven for an hour . . . That is 3 hours of [Valerie's] day. (J3,2,11)

The trip from Lari's home to the large regional hospital where her daughter received occupational and physical therapy took approximately 30 minutes. Lari explained, "That's a hassle . . . Parking is such a nightmare,

it takes me just as long to get from the [freeway] exit into [the hospital] as it does for me to get from my house to the exit" (L2.12,15).

In addition to the inconvenience of transporting children to services, these mothers experienced the additional anxiety of having their very young children away from home. Suni's daughter April originally had visits from a home interventionist. However, the home interventionist recommended that she be enrolled at the local early intervention center, where she could have social experiences with other children and begin individual speech-language, physical therapy, and occupational therapy sessions. Suni had a difficult time adjusting to this type of intervention services. "As a stay-at-home mom, I feel really guilty about that. She is so tiny, and yet I'm sending her off to school [4 days a week], but she needs it, so I am accepting it" (S1.18,16). Rani, who saw Steven enrolled in an early intervention center at 15 months, voiced similar concerns, "It's hard to send your little one off to school that early, but I felt like for Steven it was a necessary thing, even though it is hard to let a child be out of the home" (R1,7,6).

Clearly, by disregarding the federal mandate to provide early intervention services in natural environments, the local early intervention program added additional stress and anxiety to these mothers' lives. These placements had several problems built into them. First, mothers were required to disrupt the routine of their lives by scheduling frequent

and multiple appointments for their children away from the family home. In addition, the amount of time required to transport children to and from therapy appointments increased when mothers were not able to access services in their local communities. Finally, some mothers expressed anxiety and guilt regarding having very young children away from home for long periods of the day when enrolled in early intervention center services. Adding to these mothers' complicated lives was the necessity to interact with multiple service providers. The following section addresses the relationships these mothers sought with service providers.

Establishing Relationships with Service Providers

Families play a crucial role in the lives of infants and toddlers. Both the literature and Division for Early Childhood of the Council for Exceptional Children Recommended Practices (2000) are replete with indicators extolling the efficacy of family-centered practices. Bailey, Buysse, Edmondson, and Smith (1992) report that involvement of families in the intervention process is empirically shown to be more powerful than interventions focusing only on the child. Trivette, Dunst, Boyd, and Hombly (1995) emphasize that in following a family-centered model, professionals attempt to intervene in ways that are responsive and committed to supporting and strengthening families. Professionals can only be responsive when they demonstrate positive interpersonal communication and show respect for families' priorities. Regardless of what a

professional's specific discipline might be, early intervention program personnel are expected to be proficient, to exhibit a positive attitude towards children and families, and to provide services in a manner that strengthens and enriches a family's capacity to care for a young child with special needs.

The mothers in this study wanted to feel confident that each interventionist serving their children was competent. Lori spoke positively regarding the knowledge and skill of Megan's first home interventionist

She just knew everything, massage, and all kinds of stuff. She gave us information on the vitamins, she gave us information on the massage, and she gave us information on everything. And she just seemed to have all the knowledge. I don't know what we would have done without [her]. She knew everything. (L1,16,15)

Besides high-skill proficiency, Tami valued how Daniel's first service provider shared knowledge of the early intervention program

She was just incredible, very motivated, very skilled . . . She was just so good with babies. And she was such an advocate. She let me know what my rights were at almost every visit. If I had a question, she'd know what legislation was out there. (T2,5,19)

Rani's description is representative of the experiences of the 6 mothers in describing the process of becoming comfortable with service providers

When initially assigned, I was just a new face there as far as I didn't know them and they didn't know me. It was only through visiting with them and seeing them with my child, and just kind of getting a feel for their experience and how I felt. It was just an intuitive thing with that person. (R4,4,15)

Clearly, mothers expected a high level of proficiency on the part of service providers. Mothers indicated, however, that in addition to high skill levels, service provider attitudes were an important facet contributing to their overall satisfaction with services. Joni credits one service provider's attitude with the progress she sees in Valerie, "he enjoys what he is doing, which is great for Valerie. He would do it for free" (J2,4,7). Rani emphasized the importance of attitude, "[effective service providers] seem to just take a personal interest, to speak with the children at their own level, and mainly just look at their attributes rather than their deficits" (R4,1,12). Tami mentioned other positive qualities

I think my main desire, and I don't think this is something you can train in a person, I think that you either have a heart for children or you don't. I think this is an aspect of professionalism that has led me to feel that somebody was totally professional, was somebody who had that deep, not an empathy, but had that deep love and deep interest, and treats each child as an individual. (T4,1,3)

Suni addressed the importance of personal aspects of the relationship with a service provider, not just from the perspective of her relationship with April, but also with herself

She has really taken a liking to April, so when April comes in the room she always greets her. She talks to me, and we talk about other things besides just April, which is really nice. I mean, just like friends. (S2,17,2).

These examples of positive attitudes reflect but one facet of successful family-centered practices.

An essential aspect of the early intervention program is the concept of enriching the family in order to build upon their strengths. Mothers overwhelmingly preferred this family-centered approach because it was important for them to feel a personal as well as professional relationship with therapy providers. Joni described the multifaceted attributes of her home interventionist in addressing the needs of the family

I think she is wonderful. I don't know if it is what she is supposed to do, but she catered to my needs. She ministered to what I needed so that I was able to let go and let her work with Valerie. And she is real good about working with Valerie and [her older sister] together. (J3,2,2)

When asked about an outstanding service provider, Roni also described a professional who had supported her as Steven's mother

She was just so open and wanted me to talk and express how I felt. It wasn't like she was constantly opening a wound up again, but she was just—she let you know that it was okay to feel that way, and that many have walked this path, and that it is not an easy one. She wasn't underplaying it either. She knew how hard it was. (R2,22,3)

Boni reported a similar relationship

We love [our home interventionist]! She has provided a lot of support. She'll get all sorts of information if we need it. And with her, I feel like I get an honest answer. We ask her all sorts of questions, and she is just very willing to answer them if she can, and she'll tell us when she can't. We have some great discussions. And you can tell she really cares about Derek a lot, she's just very loving. (B2,3,1)

Overall, these mothers detailed the attributes they seek in professionals to include skills (competent, dependable, and knowledgeable) and attitude (accepting, caring, considerate, and

motivated). They placed a great deal of emphasis on the ability of the providers to provide family-centered services by interacting not only with the child, but also with themselves and other family members. The perceptions these mothers had of the personal characteristics of service providers were closely aligned to their satisfaction with early intervention services.

When services are not family-centered, resulting in strained relationships between parent and service providers; parents may seek new service providers. Although the mothers in the study overwhelmingly described service providers as skilled and competent, 3 of the participants described instances of changing service providers because of dissatisfaction in the way services were being delivered. Rani explained

If I wasn't pleased with what I saw them doing with my child or the progress they were making, I would request another therapist. I wasn't shy about that. I just felt like if it wasn't a good match, if we all three of us weren't a good match; I just felt like some worked better with us. (R4,4,19)

Jani also stressed the value of family-centered intervention from the perspective of an unsatisfactory relationship

We had an occupational therapist from the school system coming to the house, but she seemed to have a problem coming here. She had a problem with [Valerie's sister], she had a problem with my presence. And Valerie wasn't working well with her. (J2,19,2)

It was evident that this service provider was not willing to honor Jani's desire to have the family vitally involved in services. Because of this mismatch, Jani requested a change in providers. Similarly, Tami viewed

her participation in Daniel's services as important. She reported that what she observed and learned watching therapies contributed to her own ability to promote Daniel's growth in the home environment. Sadly, Tami also found that not all service providers welcomed her participation in the sessions. She related this instance contrasting a former occupational therapist with her current provider

Daniel cried when she first started to manipulate him and he would look at me, and I started to cry, so she asked me to leave. I refused. For a month I refused. [There was] constant stress between her and me. I finally walked out . . . I felt like I wasn't part of it, I wasn't learning anything . . . In the [current] occupational therapy session, [the parent is] not allowed to leave. They think of things in the middle of sessions that they might want to tell you. (T2,21,1)

Although Suni had not yet requested a change in service providers, an uneasy relationship caused her to question whether or not she would continue receiving services from one individual

I'm not super happy with her occupational therapist. It's not that I'm unhappy, but I'm not super happy. I haven't really looked at other options . . . She just doesn't relate to parents that well or listen to me that well (S2,8,18). I have had same concerns about her interactions with me as April's mom. (S2,11,6)

These mothers did take risks, however, in requesting a change in service providers. Because resources may limit the number of personnel available to work with children, mothers may find themselves waiting for services to be established with a new service provider, while in the meantime, their children receive no services in that particular developmental domain.

Sometimes, there may even be repercussions. Rani described one very uncomfortable situation after changing service providers

I spoke with the supervisor and said I thought the individual was doing a great job—it wasn't anything personal against the therapist, but that I felt that Steven might be best suited trying with another therapist, so the change was made. The [first] therapist took that very personally and came in another therapy session and sat down in there with the new therapist and me. [She] was kind of really upset. I just never expected that, because it wasn't handled professionally. (R4,5,21)

The experiences of these mothers emphasize the importance they placed upon the relationship with service providers. It was not sufficient for them that the service providers were skilled. Indeed, competency was viewed as a taken for granted expectation for any provider working for the early intervention program. What these mothers viewed as variables were the attitudes of the providers, both towards the child they served and towards themselves as the child's parent. These attitudes contributed to the mothers' perceptions of the service providers' willingness to provide family-centered services. Thus, a critical component of the child's interventions became the way these mothers were invited and included as part of the therapy process. In the next section, I report on the additional challenge of establishing new relationships with service providers when trusted providers become unavailable.

Establishing New Relationships Due to Staff Relocating or Taking Temporary Leave

An issue facing many early intervention programs is the challenge of finding and retaining sufficient qualified service providers. Besides the numbers of early childhood special educators (developmental specialists) required by the program, many related service personnel such as speech-language pathologists, occupational therapists, and physical therapists are needed. It is often difficult to find related service personnel where remuneration in rehabilitative services far exceeds that in pediatric services. Three of the participants reported being forced to change service providers when the ones they'd used changed jobs, left the field, or took temporary leave. As Jani related, "she got pregnant, she couldn't come for a while, and then when she came back she was spread pretty thin and our appointments conflicted with hers (J3,11,7). Lori and Rani both had service providers with whom they felt comfortable, but, as Rani explained, "I found a therapist who was great, and then she moved" (R4,9,7). Thus, these mothers found themselves once again faced with establishing relationships with new service providers. These problems were compounded when staff vacancies were not expeditiously filled due to lack of funding or difficulty finding providers willing to take an pediatric caseloads. When this happened, the mothers reported that frequency of services was impacted, and the choice of providers limited.

Two of the mothers in this study faced an even more challenging situation. They were required to reestablish the entire scope of services for their children after their families relocated. After their children were enrolled in early intervention program services, both Lori and Tami moved to different states. The circumstances of the moves, however, were very different. As she was finishing her enlistment in the military, Lori and her husband planned to move back to Florida where they could be closer to their families. She contacted the early intervention program in Florida and explained the services Megan had been receiving in Texas and provided a "heads up" to the service coordinator so that similar services could be procured. However, despite this advance planning, it was difficult to leave service providers with whom both Lori and Megan were comfortable and face the uncertainty of new service providers. Lori felt that Megan lost valuable intervention progress in the interim while reestablishing services and bringing new providers up-to-speed with what had been provided in Texas.

Tami's situation was a bit different. Facing extreme difficulties getting Daniel evaluated to determine his eligibility for services was just the beginning of her trials. Daniel was placed on a waiting list due to the lack of service providers in their area. She recalled the frustrating circumstances after talking with the service coordinator in California, her former home. "There were just no services out there, nobody was calling

me back, nobody would take Daniel" (T2,17,7). Frustrated with the system, Tami began calling different states to get information about their early intervention services. She related the incident that led her to move from California across the country to her home state of Florida

I called [a person at the early intervention agency]. . . . She took all the data over the phone and she scheduled us an appointment to get right in. So I packed up our bags and we left. I mean, I got off the phone and I cried for hours, I just couldn't believe it. I said to her, "is it conceivable that within a month or two I will have services?" and she said, "absolutely" (T2,17,21). So I was on a plane a couple of weeks later. My husband stayed and said everything and then came. (T1,26,7)

Tami's adjustment to new service providers, therefore, was mediated by two positive factors. First, Daniel was finally able to receive the service for which he was eligible. Second, Tami established positive contacts with the Florida early intervention program through the telephone conversations held prior to the move. Although both Lori and Tami linked up with services in Florida, these mothers did face several challenges in re-establishing services after moving including building rapport with new service providers, orienting themselves to new service locations, and scheduling services around other family commitments.

Three of the 6 mothers in the study reported the challenge of changing the personnel serving their children due to staff relocating or temporarily leaving the program due to pregnancies or other family circumstances. Two additional mothers reestablished their children's entire cadre of service providers after relocating. Yet additional

challenges were ahead for each family in this study due to federal policies as they prepared to transition from early intervention under Part C to pre-kindergarten services under Part B of IDEA. The following section details the concerns faced by 3 of the mothers in the study as the children approached their third birthdays. The other 3 mothers had not reached this phase by the study's end.

Transitioning to Preschool Services

At the time children turn 3, responsibility for their services moves from the early intervention program (Part C of IDEA) to preschool services as administered by Part B of IDEA. At this time, the emphasis from *family-centered* services to promote the child's development changes to an emphasis on *child-centered educational* services. Even when services are seamless, the transition from Part C services to Part B services is often a time of stress and anxiety for families. Families often must adjust to a completely new cadre of service providers, who may have limited knowledge of family concerns and priorities.

During the study 3 of the 6 mothers, Rani, Joni, and Tomi faced their children's third birthdays. At that age, their children were required to transition from early intervention services to services provided by their local school districts. Each of these mothers experienced stress and uncertainty as the transition approached. Rani talked about her perceptions of the change

I'm not comfortable with the transition process. The way it's handled is very abrupt, a very abrupt cut off at this point . . . I told some people at [the early intervention agency], that if we as adults one day worked in one particular place, and had worked there for quite a while and were very familiar with every one, and the very next day we were told we were going to be working in a brand new facility with all new folks. Well, that would be very uncomfortable. And I said, exactly, that is how the children feel. (R2,17,14)

Clearly Rani's fears included concerns for how Steven would adjust to a new environment, new teachers, and a longer school day. Although both she and Steven visited the school where he would be receiving services, she felt the change would be abrupt and disorienting for him.

Joni voiced similar concerns about the change

We're going to lose our [early intervention] services in July so time is running out. Then she will be in the school system. In a meeting I attended yesterday I was really disappointed about what I was hearing [from the other parents] about the school system. More challenges to look forward to [sighs]. (J2,20,14)

For Joni, several factors contributed to her anxiety. Due to the severity of her condition, Valerie's services had been either delivered in her home, or with Joni in attendance. The thought of releasing Valerie into the care of strangers was very stressful. She was also concerned about the frequency and intensity of services that the school district would be willing to provide. In addition, Valerie's ongoing health problems raised the level of anxiety. This, combined with the challenge of becoming acquainted with the new service providers was almost overwhelming.

Tami confronted additional difficulties with the transition process. Daniel was enrolled and receiving early intervention program therapy services in an inclusive childcare setting consisting of children with and without special needs. Because of the progress he had made in this setting, Tami requested that the school district deliver services in this same setting after Daniel's third birthday. She described the situation

The lady [from the school district] who was in charge of our [transition] meeting kept telling me that Daniel belonged in a classroom with all special needs kids. And that was something that we couldn't accept. That was something we went into the meeting knowing we were not going to accept. I never argued with her, I never got inappropriate in any way. I tried very hard to change her mind and let her know what was appropriate for Daniel. I asked questions like, "Have you ever been to [the child care setting] to observe Daniel?" And of course they hadn't. I really tried to express to them what it is that I see there. How Daniel doesn't know that he has special needs. How Daniel is expected to communicate. How all of the kids accept Daniel with his differences. And you know I got the rolling eyes. It was a long meeting. (T4,33,1)

Clearly, if the family-centered model had been followed during this transitional phase Tami's request would have been given more respectful consideration.

The transition phase was a very stressful time for each of the 3 mothers whose children were anticipating transition to preschool services. Some of the challenges faced by these 3 mothers included the abruptness of the change, the requirement to establish relationships with new service providers, concerns for children being away from home for longer parts of the day, health issues, and the switch from a family-

centered model of service delivery to that of one focusing on the child's educational needs. Additionally, 2 of the 3 children's placements would be in public schools, where there is often a culture of detachment from home or family contact. One of the goals of the federal Early Intervention Program is to empower families to meet the challenges that come to them as they advocate for their children. Yet the agencies' switch from family-centered to child-centered educational services disempowers many families. As families attempt to be advocates through the transition process, they are sometimes overwhelmed by new and different requirements of the educational system [public elementary schools] that presumes to know what is best for all children with special needs at age 3.

Summary of Delivery and Reception of Developmental Services

The children in this study had different disabilities and challenges and each family experienced a different journey through the early intervention system. Four significant events impacted the delivery and reception of developmental services. These events are navigating among service delivery models, establishing relationships with service providers, establishing new relationships due to staff relocating or taking temporary leave, and transitioning to preschool services.

Each of the 6 mothers was involved in both home-based and center-based services. Mothers faced significant challenges due to transporting children to center-based or private therapies, especially Lori,

Tomi, and Joni, who each lived a substantial distance from the service providers. Besides the disruption of family routines required by transporting, services were fragmented. Providers had little if any contact among them as services were provided in several different venues. Some mothers also experienced separation anxiety due to having their young children enrolled in center-based services for a significant portion of the day.

The importance of establishing good relationships with service providers was emphasized for these mothers, as they were required to build rapport with each service provider. The mother indicated that their children had received services from a variety of providers. At times, providers changed at mothers' requests; however other changes occurred due to providers no longer being available. In addition, 3 mothers prepared for changes prescribed by law as their children prepared for transition to preschool services. Regardless of the reason, the mothers reported that their children's services were disrupted while changing providers. The perspectives the mothers had of the process of navigating the system were as personal and individual as their specific children and families. In the next section, I report the mothers' reflections on the methods service providers utilized and their suggestions for improvement in the early intervention system.

Looking Back: Suggestions for Improvement of Early Intervention

The 6 mothers in my study described the ongoing process of evaluating the types of services their children were receiving. As advocates for their children, they were constantly assessing how both the early intervention program and individual service providers interfaced with their child and family. As these mothers discussed their experiences in navigating services for their children from diagnosis of disability, through various stages of service delivery, and on to the transition from early intervention program services to preschool services, they suggested ways the process could have been easier for them. In addition, they revealed their perceptions of the level of spousal support they received.

Suggestions for Early Intervention Services

The voices of these mothers are emphatic in regard to the frustrations experienced in navigating the early intervention system. Primary for all 6 mothers is concern regarding the manner in which these life-altering diagnoses are delivered. Three of the mothers made specific recommendations regarding who should deliver the diagnosis and what information should be immediately presented to the parents. Boni was very unhappy that the initial indications that Derek may have Down syndrome were presented to the family by a nurse practitioner. She suggested, "the pediatrician should have examined the baby, and then told us about it" (B1,21,20). Clearly the nurse practitioner was not qualified

to make the diagnosis, and the alarm Boni and her husband experienced in waiting for the physician to make an official diagnosis increased their level of anxiety.

In contrast to who delivers the diagnosis, Lori, Joni, Tomi, and Rani had suggestions for the supports that should be present for the family at the time the diagnosis is delivered. Lori recommended

Maybe having a psychologist on hand, someone who could have come and said, "you guys are going to be okay, this is no big thing." Maybe someone to come in and talk to us specifically about Downs It would have been so great to have someone come in and say, "here is a picture of a family I know with their Downs kid playing soccer. Or "here is her first birthday" or "here is this" or "here is that." I needed someone to say "it's going to be okay, she is going to be normal for the most part" (L1,27,2).

Joni concurred with this need, emphasizing, "You need someone to help you see wonderful things about [your] child, even though it wasn't quite what you had planned" (J3,16,4). Rani suggested

I think if you are a person [delivering a diagnosis] you have an obligation to the parent to have done your homework before you present something to them, as far as to say, "Here are resources. I looked online, and here is a parent's support group. Or I have a counselor here who would like to talk to you, if you would like to talk to him" (R2,3,1). You don't know what to say to someone if they did say, "how can I help you"? But just to have someone . . . to talk with you, or if you are a religious person to pray with you there. Something! I mean this is big! (R3,19,13).

Tami expressed concern that information was not readily available to her at the time of Daniel's diagnosis.

I think sometimes [professionals] are afraid of giving you too much, thinking that they might be inundating you with information, especially in the beginning. They may think that you don't

understand, or don't want to understand. But it can never be too much, because they don't know at what point and time it will be just the right information to help me get past a tough time and move ahead in understanding Daniel's diagnosis. (T4,29,2)

The suggestions these mothers offer to professionals align with three important adoptive coping strategies: reframing, seeking information, and turning to religion. Clearly these mothers, confronted with their children's devastating diagnoses, sought support from the professional delivering the diagnoses to assist them in the initial steps of adaptive coping. Lori's recommendations emphasized her need to reframe her limited current understanding regarding Down syndrome to view this diagnosis from the perspective of families who are successful in dealing with this same diagnosis. Similarly Joni, overwhelmed with the severity of Valerie's diagnosis, expressed a need for supports in seeing past the disability to the child.

All 6 mothers' recommendations for service providers included the provision of information as a vital requirement for them to be able to cope with their children's diagnoses. Boni summarized the concerns that were evident for all the mothers, "it's just the information gathering at the very beginning that was so difficult" (B2,4,2).

Rani's suggestions include the provision of information, but in addition she mentions area of turning to religion. Suni stressed, "I understand all that about separation of church and state, but I also think it is important that professionals don't downplay the strength that I receive

from God" (S3,14,3). It is obvious that as these mothers reflected on their experiences of receiving the diagnosis, they identified ways in which professionals could have better supported them in beginning the adaptive coping process after receiving the initial diagnoses.

Once the diagnosis was made, these mothers continued to experience difficulties in discovering and accessing the early intervention system. When asked what changes she would make to early intervention program services, Boni suggested

[I would have changed things] in the beginning, that it would be easier, that I wouldn't have had to push so hard. [I wish the early intervention program] was something that would have been easier to find out about . . . I think when a child is born or is suspected or whatever that someone contacts the family and says "it's okay, there are all these things that you can do that are going to make a significant difference." Just some interaction with someone . . . So I guess my concerns would first be information about what is available, followed up with help to access those services. I think you need to find one person. If you can just get contact with one person to find out how to maneuver the system, that would make a huge difference. (B2,4,6)

Rani had similar suggestions

I think [it would be a big help] just initially giving the parents the information about the early intervention program, because I had no idea that it even existed. I had to seek out the early intervention specialist to come to the house. There were all the months in between birth to when we got in that Steven could have benefited from that. But we just kind of got that information in passing when we were talking to a pediatrician. (R3,15,13)

Tomi, Joni and Suni had frustrations that stemmed from the time it took to get their children into services. Suni explained the wait involved before April enrolled after she was determined eligible for services

The waiting time to get her in was the only thing that I had concerns about. It was just the circumstance with that, if they have too many kids, they have too many kids. I guess you have that problem which involves waiting lists. (S2,11,21)

Analysis of the stories related by these mothers provides insight into the importance of their interactions with early intervention services. These mothers ask that first and foremost service providers help them help their children. They want to be involved because throughout all the changes, the parents remain a constant in the child's life. Rani eloquently described reasons why service providers need to actively support the parents

Support means not only to be there for the kids. Parents are the child's main life support to everything. If the parents are suffering, and if we have a flat tire in our emotions, the children are going to suffer, because obviously they live with us for the majority of the time. We are their link for services. We get them there. We are the link with the professionals to get things set up with the children, to just get their whole lives in order. We are totally responsible. I just feel like we also need some support. I don't know exactly how, but I just know that it was a very lonely process. (R3,21,3)

The suggestions these mothers made for the early intervention program included the provision of emotional, informational, and spiritual supports at the time of diagnosis, more direct information about the program, and more ready access to the program. Although understanding of the demands on the system, these mothers also expressed concerns regarding waiting lists that slowed their children's provision of services.

Spousal Support

Although the mothers' suggestions that emerged while looking back at their experiences did not directly focus on the fathers, they did share their perceptions. Because the entire family system is impacted when a child is identified with a developmental disability, I want to acknowledge the mothers' reports of the roles these fathers played throughout the diagnosis and early intervention process. All 6 participants indicated that they were in stable marriages and that the fathers were present at the children's diagnoses. Yet these fathers were often perceived as the silent partners. From the mothers' perspectives, fathers assumed one of three levels of involvement. Boni reported that her husband actively researched Derek's diagnosis, participated in his IFSP development, and attended many therapies. This role represents the highest level of involvement. Other fathers showed support by searching for a diagnosis and attending initial IFSP meetings, but the mothers felt that discovering and accessing services were tasks left to them. Last, some fathers were reported as being involved only when the initial diagnosis was delivered, providing little or no help while discovering and accessing services or participating in ongoing therapies.

Summary of Looking Back

Despite the challenges that these mothers encountered as the result of having children with developmental disabilities, they each valued

the association that they experienced with service providers. The mothers expected that providers would be skilled, caring, and family-centered. The 6 mothers prioritized family-centered methods that focused not only on the needs of their child, but also addressed the family's needs. The mothers desired to be included in their children's services and to feel a personal relationship with the service providers. The mothers expected that providers would be skilled, competent, and caring.

The suggestions these mothers had for the early intervention program also revolved around family-centered methods. The mothers desired that the delivery of diagnoses and the supports for families at the time of diagnosis would be sensitive to the needs of the entire family, including providing information or contacts. The participants were frustrated with the difficulty in accessing developmental services and the stress that transporting children to multiple and distant services placed on their families. These mothers' relationships with service providers were vital to their overall experience with the early intervention program. Thus, interviews with service providers and observations of parent-professional interactions were conducted to add strength to the data and to help determine if and how professional training and attitudes contribute to family-centered services.

Family-Centered Practices: The Professional Perspective

In order to enrich the data concerning parent-professional interactions and provide analytic triangulation, I observed eight therapy sessions of those mothers who participated in their children's therapy sessions (one service provider was observed twice because she provided services to two of the children). I then conducted 45-minute audio taped interviews with the 7 observed service providers. Two sets of data were generated, (a) post hoc notes from the observations and (b) transcriptions of the interviews. Table 5.1 provides demographic data on the service providers showing their area of professional training, years of experience, and setting.

None of the 7 service providers interviewed and observed indicated that family-centered methods were included in their pre-professional training programs. Although this may have been expected from related service providers (speech-language pathologist, occupational therapist, physical therapist), the emphasis on family-centered services is typically included in early childhood special education training programs. It should be noted, however, that Gina's work in early intervention spans over 20 years, and she received her pre-professional training in a western European country. Thus, the majority of training these professionals had received relative to family-centered methods was provided as inservice through their agencies, as subsequent courses to maintain licensure, or

Table 5.1

Service Provider Demographics

Name	Discipline ^a	Serving	Experience	El Experience	Setting
Anna	SLP	Tami	20 years	12 years	Center-based
Becca	SLP	Lori	5 years	3 years	Private
Cara	SLP	Suni	1 year	1 year	Center-based
Dana	OT	Tami	8 years ^b	20 years ^b	Center-based
		Suni			
Emma	PT	Boni	26 years	13 years	Private
Fonda	PT	Lori	6 years	3 years	Private
Gina	DS	Boni	22 years	22 years	Home

Note. ^aSLP = speech-language pathologist, OT = occupational therapist, PT = physical therapist, DS = developmental specialist. ^bDana worked 12 years as a developmental specialist prior to completing her studies in occupational therapy.

by reviewing modules provided by the Florida Part C early intervention program. Service providers expressed concerns that this type of training wasn't more consistent. Cara reflected on the trainings received through the early intervention program and noted, "It's not really that organized. So [training in family-centered services] probably doesn't get updated like it should because we have new people filtering in. We are required to update occasionally, I'm not sure, every 2 or 3 years (SPC,3,8). Dana agreed that "unfortunately there is not a lot of time for training, probably

not as much as there should be" (SPD,5,14). Emma indicated that neither she nor her partner in private practice had received any training in family involvement from the Part C Program (SPE,5,2). The same was true of Becca and Fanda who are also in private practice (SPB,3,5; SPF,4,130).

Since beginning their employment in early intervention, some professionals had taken additional college level coursework relative to serving younger children with disabilities. Anna recalled a specific incident from one of these classes that "helped shape my perspective of working with families" (SPA,12,18). She explained

There were several people like myself in the class that were [working] professionals, and, that were taking the class for whatever reason, for the experience. And I remember we had to do some kind of group presentation. One of my colleagues, in her presentation, wasn't being very family-centered. And [the professor] let her know with no bones about it. I think it was a hard learning experience for her, but so important for all of us from the things that we learned from that experience. If I had to point to a college class [that influenced how I work with families], that class did more than any of the speech classes I had taken ten or twelve years earlier. (SPA,12,20)

Emma took subsequent coursework geared toward pediatric populations in order to maintain her licensure. However, the methods she learned from her coursework involved a more professional-directed approach to working with families rather than promoting an interactive relationship between families and professionals. She explained that these courses were

treatment approaches for working with children with various disabilities, and then as we would learn what to do, there was usually a focus of the end, it might have been short, about how to get families to follow through with that. And, if some of the techniques were too involved, how to get them involved with this follow-through on a more limited basis. (SPE, 5, 8)

Four of the service providers (Anno, Cara, Dano, and Gina) were employed by a local early intervention center that contracted with the Port C early intervention program to provide services. Although these interventionists worked for the same agency, there were different perspectives expressed when asked, "What is the policy of your agency regarding family involvement?" Anno's view of family-centered services was very reciprocal, as she explained

We try to be very family-centered, both in what we focus on goal wise for the child and then encouraging families to be a part of whatever we do, at whatever level they want to be. If they want to spend time in the classroom, if they want to participate in therapy sessions, whatever their choice is. (SPA,2,5)

Gina expressed very similar perspectives of family-centered services as those purported by Anna, yet her understanding of the philosophy was applied more to the individual wishes of the families as far as the type of services they desired

Family involvement is a very broad and personal thing for most people. The family involvement here is to try and connect with the families and determine what they want for their child. At least that is what I see my role as when I go into the home. (SPG,6,3).

In contrast, Dano's explanation of the agency's philosophy represented a very professional-directed model of family participation.

She indicated, "what we do here has to be carried over at home" (SPD, 2,2) and "the hardest families to deal with don't follow through" (SPD,2,10). She also expressed concerns about "some very over-protective parents [who are] not willing to let the child separate [from them during therapy]" (SPD,3,1).

Coro's explanation of the agency's philosophy seemed to fall somewhat between that of her colleagues. Although she expressed the desire for partnering with parents and "helping them feel as comfortable as possible with the therapy process" (SPC, 2,6), her perspectives still seemed to be somewhat professional-directed relative to families following up on homework assignments and carry-over of therapy goals into the home environment (SPC,2,18). However, there was none of the negativity towards family-involvement as was evident in the interview with Dono. Part of the discrepancy between perspectives may have been the longevity of these professionals in the agency and the different supervisors with whom they had worked. Cara had only been at the agency for one year, and had received no formal training on Port C early intervention program policies or on family-involvement. It is possible that Coro was still seeking to develop her own perspectives relative to family-professional interactions. While Dono's perspectives may have some basis in the traditional medical model of service provision seen with occupational therapy, she had a long history of working in early intervention prior to

making the career change to occupational therapy. It may be that some professional opinions regarding the benefits of working with families are deep rooted and difficult to change.

The 3 service providers in private-therapy settings acknowledged that they did not have philosophy statements in place relative to family-involvement. Emma indicated that she and her partner in the practice share a similar philosophy

We hope to give parents lots of support and encourage them to keep going. Since they see their child every day, they may not notice the amount of growth the child is making. We try to help them celebrate the progress their children make. (SPE, 6,13)

Becca's and Fanda's practices were both administered through a large regional medical center. Although they originally served Lari's daughter Megan through contracts with the early intervention program, at the time of interviews, they were being reimbursed through private insurance. They shared similar perspectives on family-involvement in regard to the "carry-over of what I'm doing in therapy to the home environment" (SPF,4,20) and "to have what goes on in therapy be valuable for what the parent tries to do at home" (SPB,6,1). They both valued the interactions with families, but it is possible that their medical setting limited the perspectives they had in regard to reciprocal benefits to therapists from the families because infants and toddlers were a very small portion of the clients they see.

All of the service providers indicated that family involvement in the therapy process provided benefits to the child's development. Even Dana's comments showed her awareness that service providers should involve families. Providers used terms such as "carry-over," "generalization of skills," and "incorporation of skills in the natural environment" to describe primary benefits. However, Anna described the benefits to the child's development that were evident because she, as a provider, learned from the family

If I've had any "aha" experiences, it has been through direct work with families. The family we both know, [Tami and Daniel], is a good case in point. There are things that his mom can get him to do that were "ahas" and I've watched her style and seen how she gets her child to respond. So I've learned from her. I've watched the way she cues her child and have seen that her child responds a lot better.

Then there are the times when the family has a certain perspective on what they want to focus on. Maybe I was focused in a different direction, and I realized they are more concerned about something else. So that kind of shifts the focus, and that is a focus that works a lot better because the family guides it. (SPA,4,3)

This type of reciprocal benefit between family and service provider was also evident to Gina in her interactions with families. She explained

As I watch parents interact with their children, I can learn the ways that the child is more likely to respond. When parents see me incorporate some of their techniques, it builds a level of trust between them and me. This encourages parents to feel confident in their ability to interact with their child and to enjoy their child. (SPG,8,14)

The eight observations of parent-professional interactions during therapy sessions provided substantiation for the interview data. Although

the service providers differed in the approaches they took during therapy, it was evident that these providers were concerned not only with the children's development, but also with the role the parents played in promoting development. All of the sessions included some level of hands-on involvement by the parents. Gino, Anna, and Becco involved the mothers throughout the entire session. Coro, Dono, Emmo, and Fondo all provided time for the mothers to practice techniques at the end of the session. Each service provider gave information on activities that could be done at home to help promote further development.

With the exception of Dono, all of the service providers appeared to show a genuine interest in the mother, not just the child. This was shown through friendly conversation before and after sessions, and by inquiries about family activities. For example, Emma asked Boni about Derek's grandmother, and when she would be back in town. Fonda and Becco both expressed excitement about Lori's upcoming family vacation. Anno was aware of Tami's transition meeting with the school district, and inquired about how it had gone. In contrast, during Daniel's session with Dono, Tami initiated the discussion about the transition meeting and also offered information about what Daniel had been doing at home. This some distancing between the therapy setting and the child's home environment was observed during April's session with Dono. Although Dono provided Suni with directions for activities that could be carried out

of home, there was no inquiry about what she was observing April do in the home environment. These 2 mothers approached each of the service providers the same way, however, the interactions differed depending on whether the service providers' methods were family-centered or not.

Summary of the Professional Perspective

Although all 7 of the service providers provided services to children enrolled in the Part C early intervention program, there were differences among the providers. None of these service providers had received pre-professional training that included components of family-centered practice. Although there was a section on family-centered practices included in the early intervention program training modules, trainings were described as either "non existent" or "inconsistent."

Four of the 7 service providers worked for the same early intervention agency. Yet even among these providers, the perceptions of the agency's philosophy on family-centered services differed. Those service providers involved in private practice indicated that there was no written policy regarding family-involvement.

All 7 service providers acknowledged the importance of family-involvement in the therapy process. Yet the general consensus appeared to be a one-way benefit, that of benefit to the child and family in increasing the child's skill ability. This was evidenced through the use of terms including "generalization" and "carry-over" of skills. However, 2

service providers, Anna and Gina, did recognize and acknowledge the benefit and reciprocal nature of family-centered services. Both of these professionals commented on the professional growth they had obtained by tuning into families, observing parents' interactions with their children, and listening to their priorities for therapies.

Summary

The mothers' experiences in this study underscore how persistent and resilient they must be when coming to terms with their children's diagnoses of disability and through subsequent interactions with service providers. Based upon the participants' individual stories of coming to terms, five significant stages emerged. The first, *Becoming Aware: Something is Very Wrong*, was detailed in chapter 4. The other four, dealt with here, include: (a) *Discovering, Seeking, and Finding Services: Awareness of Early Intervention*; (b) *Enrolling in Services: Access to Early Intervention*; (c) *Learning the System: Delivery of Services*; and (d) *Looking Back: Suggestions for Improvement of Early Intervention*.

In most cases, mothers had difficulty discovering what services were available and felt that the medical professionals were reluctant to make referrals. Regardless, mothers believed that information concerning services, or at least a contact, should be given to parents at the time the child is diagnosed. Despite the fact that a child is legally supposed to be enrolled in early intervention services no later than 45 days after referral, 4

mothers had to aggressively assert their rights in order for this to happen in a timely manner. This is due to understaffing and high demand. One mother encountered such difficulty receiving services in California that the family relocated to Florida where she was assured her child would be enrolled in services right away. In addition to relocations, interruptions in children's services arose when care providers moved away, changed jobs, or took a leave of absence. Therefore, even after children were receiving services mothers still could not relax because there were always new policies to understand or new situations to trouble-shoot.

Throughout these experiences, mothers expressed the most satisfaction with service providers who showed care and enthusiasm in their work, were skilled at answering parents' questions and providing further information, and practiced family-centered methods. Though all but 1 of the service providers observed and interviewed emphasized family-centered methods, they stressed that they received little training in this area. Only 2 of the 7 acknowledged the reciprocal benefit of using family-centered methods; not surprisingly, these were 2 of the 3 providers who had been practicing at least 20 years. It is probable that if training in family-centered methods—and the reciprocal benefits—increased, service providers would be able to implement these techniques earlier in their practice and parents would be more satisfied with the services they receive overall. For the 3 mothers who at the end of the study were

facing the transition into Part B services, the shift meant moving away from family-centered methods to child-centered methods. These same mothers who place such a high value on family involvement are faced with losing the personal relationships they'd had with service providers, in addition to the general anxiety change induces. One must question whether this level of stress is inevitable or whether it can be made more manageable by the school districts adapting a family-centered approach to the care of children with special needs after age 3.

Although in reporting the findings of this study, the steps and stages have been presented in a linear manner, I must emphasize that there are no clear-cut beginning and ending points. Rather, just as these mothers achieved a level of acceptance and understanding about one issue concerning their child's development and services, another issue often arose. The overlapping of these five stages complicated the mothers' attempts to adaptively cope with their situations. In fact, the suggestions they had for service providers targeted ways in which professionals could have helped parents reframe the problem, seek information, and turn to religion as new challenges emerged. These challenges, though sometimes related to the child's development, were at times caused by the bureaucratic policies of the service agencies or medical profession. In the following chapter, I discuss the application of these findings, address the limitations of this study, and make suggestions for further research.

CHAPTER 6 DISCUSSION OF FINDINGS, LIMITATIONS, AND IMPLICATIONS FOR PRACTICE AND FUTURE RESEARCH

Introduction

The challenges facing mothers as they receive diagnoses of children's disabilities, cope with the diagnoses, seek and find services for their children, and find a level of satisfaction with services are varied and complex. Researchers have only begun to examine the personal experiences of parents as they first learn of a child's disability, learn to function as parents of a child with a disability, and learn to cope with that reality. Parental reports regarding useful supports for coping with the stress surrounding children's disabilities can influence the behavior of service providers. In addition, this understanding can promote systemic changes by providing information that facilitates family-centered services.

The purpose of my study was to find out how 6 mothers of young children learned about, came to understand, and responded to the evolving realities of parenting a child with disabilities. I investigated several steps in the coming to terms process: (a) receiving diagnoses, (b) employing coping mechanisms and accessing support systems, and (c) establishing parent-professional relationships.

Prior research in the areas of receiving diagnoses, coping mechanisms and support systems, and parent-professional relationships primarily focused on older children (e.g., Atkinson et al., 1995; Baxter, Cummins, & Pollock, 1995; Gavidia-Poyne & Stoneman, 1997; Honig & Winger, 1997; Morgallit, Roviv, & Ankonino, 1992; Quine & Rutter, 1994; Rodrigue, Morgan, & Felken, 1990; Sloper & Turner, 1993a, Sloper & Turner, 1993b). Additionally, many of these studies relied exclusively on quantitative research methodologies. Although a limited number of studies employed mixed quantitative and qualitative measures, these studies were primarily conducted outside the United States (Atkinson et al., 1995; Morgallit, Roviv, & Ankonino, 1992; Sloper & Turner, 1993b). The literature directly studying parent-professional relationships was limited as well (Quine & Rutter, 1994; Sloper & Turner, 1993a). My findings, which rely exclusively on qualitative data, provide insights into the individual and personal challenges faced by these 6 mothers of young children with disabilities. By allowing these mothers to report their own perceptions of the reality of caring for a child with disabilities, the findings raise awareness of what issues are most important to mothers. In this chapter I summarize and discuss my findings. Following this discussion, I address limitations of the study and then present implications for future research and practice.

Summary and Discussion of Findings

The mothers in my study faced many challenges as they became aware of their children's disabilities, found supports and relied upon coping mechanisms, and established relationships with service providers. Of primary importance is the finding that during the early childhood life cycle stage, these mothers faced five significant sub-stages, each with multiple attributes. I discuss my findings as they pertain to each of the five different sub-stages.

Early Childhood Life Cycle

An important facet of the Turnbull, Summers, and Brotherson (1984) family system framework is the family life cycle. Within the family life cycle, these theorists identified two important events: developmental stages and life transitions. Carter and McGoldrick (1989) defined a family life cycle as the interactions among all changes in the family. Turnbull and Turnbull (2001) acknowledged four developmental stages that hold significance for parents of children with disabilities: birth and early childhood, childhood, adolescence, and adulthood. Specific to the birth and early childhood stage, they identify two life events that challenge families of children with disabilities: discovering and coming to terms with exceptionality, and participating in early childhood services (Turnbull & Turnbull, p. 157). The specificity of my study, however, allowed a closer examination of the birth and early childhood developmental stage than

has previously been undertaken. Each of the 6 mothers in my study participated in five significant sub-stages during the birth and early childhood life cycle stage: (a) becoming aware; (b) discovering, seeking, and finding services; (c) enrolling in services; (d) learning the system; and (e) looking back. These sub-stages are not always sequential and individuals cycle through (and recycle through) them at different speeds and sometimes in different order depending on their situation. But the sub-stages themselves are consistent and therefore useful to those who want to understand and better serve mothers of very young children with disabilities.

Becoming aware. The six mothers in my study underwent a various and complex chain of events as they first entertained suspicions that their children had developmental delays, acted on the suspicion and pressed doctors to attend to their concerns, received the diagnoses, and coped with the diagnoses.

There was variation not only in the time that lapsed between the mothers' initial suspicions and diagnosis, but also in the amount of support these mothers received from medical personnel in determining their children's developmental status. For 4 of the mothers, Boni, Lari, Rani, and Jani, suspicions about their children's health and developmental status surfaced before they left the hospital after their children's birth. Bani's and Lari's physicians pursued concerns, ordered genetic testing, and

made specific and timely diagnoses. Despite their early concerns, however, both Rani and Joni left the hospital with no definitive answers and had to stay in constant contact with doctors before they received specific diagnoses months later.

In contrast to the other 4 mothers, Tami and Suni both left the hospital under the impression they had healthy newborns. But as months progressed, they both began to suspect that something was wrong. They both found it necessary to press physicians to attend to their concerns. Despite Tami's many years as a nurse, doctors tended to brush her concerns aside. Suni, too, became frustrated as more than one physician took a wait-and-see attitude regarding her daughter's developmental status. This finding supports the work of Epps and Kroeker (1995) who found that physicians' willingness to follow up on requests for early intervention and psychological referrals and consultations were influenced by the child's level of developmental delay. At the time Tami and Suni were pressing for diagnoses, neither of their children were exhibiting severe developmental disabilities. Despite that fact, both mothers had suspicions that should have been addressed. Both turned to medical professionals, but were thwarted in their search for a diagnosis by the doctors' wait-and-see attitudes. This waiting only served to increase the anxiety these mothers felt regarding their children.

Four of the mothers, Lori, Boni, Roni, and Tomi, expressed concerns for the manner in which their children's diagnoses were delivered. The concerns they expressed centered upon two factors: the manner of delivering the diagnosis, and the lack of support for the family at the time of receiving the diagnosis. Lori and Boni were both initially aware of the suspicions that their children may have Down syndrome based upon remarks from nursing personnel but would rather have heard it first from their doctors. The issue of a family's privacy was also raised when a nurse informed Lori's husband of the nurses' suspicion that their daughter might have Down syndrome. In addition, Lori was unsettled by one doctor who told her she would not need to take her baby home since she had not known of the diagnosis prior to her birth. Roni, too, felt a lack of sensitivity on the part of the geneticist who delivered Steven's diagnosis. His cold, matter-of-fact presentation left her with no emotional support during this life-changing event. Tomi was frustrated by a physician who provided Daniel with a diagnosis of benign external hydrocephalus, yet provided her with no information on the specifics of this disability or how it might impact his development.

The fact that two-thirds of the mothers in my study felt dissatisfied with the manner in which their children's diagnoses were delivered closely mirrors Sloper and Turner's (1993a) finding that 63% of their respondents were dissatisfied with the disclosure of their children's diagnoses. The

languaging expressed by my participants for a timely, considerate, informative, and sympathetic presentation during disclosure of diagnosis supports findings of previous researchers (Elkins, Staval, Wilray, & Dacus, 1986; Helm, Miranda, & Chedd, 1998; Quine & Rutter, 1994; Slaper & Turner, 1993a) who found that parents desired comprehensive information and more opportunities for counseling and support, including having comprehensive discussions of both the positive and negative aspects of parenting children with disabilities. My findings suggest that professionals delivering diagnoses of disabilities continue to fail many families in the manner diagnoses are disclosed. These medical professionals, either unaware of or dismissive of special education's family-centered practices, are not addressing the needs of the entire family. The medical model under which they practice clearly focuses on the needs of the child, ignoring the family system through which the child is supported.

The participants in my study used both palliative and adaptive coping strategies as they coped with their children's diagnoses. Although previous researchers (eg. Atkinson et al., 1995; Margalit and Ankanina, 1991; Margalit, Raviv, & Ankanina, 1992; Slaper & Turner, 1993a) discount the benefit of palliative coping strategies in diminishing stressors, this did not appear to be the case with the participants in my study. While these 6 mothers utilized palliative strategies far less than adaptive ones, each of the participants engaged in at least one palliative coping strategy. It is

evident, however, that the use of these strategies was closely linked to the use of adaptive strategies. For example, Tami's description of slipping in and out of her husband's denial emphasizes awareness that she approached this strategy knowingly, and as a calculated time-out from reality. However, she was able to slip out of denial whenever something needed to be done or decided, demonstrating that the palliative coping was embedded within her use of adaptive strategies. Similarly, Suni's use of the palliative coping mechanism of questioning, as evidenced by her searching to discover why her daughter had delays, led her to the adaptive strategy of seeking information. It is possible that the perceived benefit of using palliative strategies may be linked to the fact that my participants were aware of their use during the time these strategies were being employed and were not solely relying on them.

Rani, Suni, Bani, and Tami each acknowledged awareness while using palliative strategies. For example, Tami asked whether you could really call it denial if you knew you were doing it. Because of this awareness, these mothers were in a position to move more easily from the use of these emotion-focused strategies to problem-solving, adaptive strategies. This is not always the case, however. The mothers in Judge's (1998) study that relied upon palliative coping strategies reported that it negatively affected their family's sense of mastery or competence. Similarly, Slaper and Turner's (1993b) participants' use of the palliative

strategy of wishful thinking was linked to poorer parental outcomes for satisfaction with life and adaptation to the child. Although I did not ask my mothers to report on issues of family competence or on satisfaction with life, the awareness my participants had of their use of palliative strategies may preclude some of the problems observed by these other researchers. Their awareness of palliative strategies may have prevented these mothers from becoming entrenched in the emotional stages of coping.

Other, the primary coping strategies used by the 6 mothers in my study were adaptive. Each of the 6 mothers related experiences of reframing, seeking information, and turning to religion. While the use of adaptive coping strategies strengthened these mothers' responses to the stressors involved in parenting children with developmental disabilities, they still reported undergoing high levels of stress. It is evident from the mothers' suggestions for early intervention professionals that the professionals delivering the diagnoses did not support these mothers in their attempts to cope.

The mothers in this study made specific recommendations for professionals to (a) assist them with reframing the situation, (b) provide information regarding diagnoses, and (c) link them with religious and community supports. These requests are clearly asking for supports that are closely aligned to adaptive coping strategies. Both medical and

developmental pre-service educational programs need to provide their students with training regarding coping mechanisms and no longer ignore this essential aspect of family-centered service delivery. Service providers must have an understanding of these strategies in order to validate family efforts and provide appropriate supports.

All 6 mothers in my study acknowledged reliance on either a higher power and/or an a church family to help them cope with their children's diagnoses. Researchers have already identified raising children with disabilities as a catalyst for increased spirituality (Behr & Murphy, 1993, Stainton & Besser, 1998, Summers, Behr, & Turnbull, 1989; Skinner, Correa, Skinner & Bailey, 2001; Turnbull & Turnbull, 2001). Yet there were differences among these mothers in the way their spiritual needs were addressed. Bani, Lori, Tami, Suni, and Rani described instances where the needs of their children had caused them to turn to a higher power, thus increasing their own level of spirituality. Joni said she turned to her congregation for support during times of crisis. McNair and Swartz (1995) conducted a study to determine what type of support churches provide for individuals with disabilities. They found that 81 percent of their respondents had individuals with developmental disabilities in their congregations and most of these congregations reported that they made an effort to provide social and emotional support for these individuals.

Joni, Lori, and Suni attended local congregations and found that the needs of their children were supported in services.

Regardless of the aid churches can provide, there may be hesitancy on the part of early intervention program service providers to validate the support families receive from religious institutions. Family-centered service providers must be trained to recognize and support families' desires to use religion as a means of coping when a child has serious health or developmental issues. Religious institutions should be viewed as another of the microsystems in which a family participates. It is best, then, for service providers to support families who chose to be strengthened by either their religious beliefs or by a church community as they come to terms with their children's diagnoses.

The Becoming Aware sub-stage is a crucial time for mothers. Four specific events—suspecting that something was wrong, acting on the suspicion, receiving the diagnosis, and coping with the diagnosis—were each evident for the 6 mothers in my study. The awareness these mothers gained was often fraught with frustration as it was necessary for them to push doctors to attend to their concerns. These mothers needed specific diagnoses in order to know what the future implications might be for their children. The manner in which these diagnoses were delivered, however, did not reflect family-centered practices. The mothers expressed concerns about the insensitivity of some medical practitioners, both

regarding who delivered the diagnoses and how those diagnoses were delivered. The mothers' suggestions for providers at the time of diagnosis align with the adaptive coping strategies of helping them to reframe the situation, providing them with information, and supporting their emotional and spiritual needs. Once the diagnoses were made, these mothers began the arduous journey of learning about early intervention services.

Discovering, seeking, and finding services. Despite the intent of the Individuals with Disabilities Education Act (IDEA) the participants in my study did not encounter a direct link between their children's diagnoses and receiving developmental services. My findings indicate that for these mothers, discovering the services available through the early intervention program was wrought with delay and limitations. Based upon the medical diagnoses of their children, 5 of the mothers should have received a direct referral to the program. Yet the only mother who was offered services directly at the time of diagnosis was Lori. Since her daughter Megan was born in a military hospital, it is possible that her direct link to services was more reflective of the military's Exceptional Family Member Program (EFMP) than of the physician's awareness of the Part C early intervention program.

The 6 cases in my study suggest that medical professionals are reluctant to make referrals to developmental professionals. I propose four possible reasons why this may be the case. First, physicians may not refer

because they fail to listen to or validate mothers' suspicions. This may result from a lack of respect for parents. Bailey, Skinner, Rodriguez, Gut, and Correa (1999) reported parental perceptions of discrimination from service providers in their study of Latino parents of young children with disabilities. These researchers found that some parents were dissatisfied with services because they felt they were being discriminated against at health agencies due to their ethnicity. It is possible, however, that all parents may be subject to levels of discrimination from physicians who fail to heed or respect parents' untrained perceptions regarding their young children. Second, physicians may possess an attitude that as physicians, they are experts, and as such their recommendations regarding the child's care should be paramount. This attitude may prejudice them against making referrals to developmental professionals who are grounded in an educational rather than medical model of service delivery. Third, the physician may prefer to wait and see how a child's development progresses rather than make a referral that would result in a false-positive determination. Physicians are often burdened with delivering bad news. They may be reluctant to diagnose a child knowing that it could have a significant impact on the family's emotions and stress. Physicians may feel apprehensive in verifying mothers' concerns as a valid diagnosis because of the uncertainty of the course of the child's development. Finally, physicians may be unaware of early intervention

program services, and thus do nothing. Despite the vital role of physicians as part of the identification process, research shows that identification and referral rates to the early intervention program are inconsistent (Bernstein, Stettner-Eaton, & Ellis, 1995; Buck, Cox, Shannon, & Hash, 2001; Minkovitz, Matthew, & Strobino, 1998). Various federal grants including C-FIT (Caring for Infants and Toddlers with Disabilities: New Roles for Physicians) and TIPS (Trends for Inclusive Pediatric Services) have been federally funded in efforts to address the problem (Connecticut University Health Center, 1997; Garland, Kniest, & Quigley, 2001). Despite these efforts, the Office of Special Education Programs (OSEP) identifies concerns with physician referral in 50% of the state early intervention programs monitored since 1997 (OSEP State Monitoring Reports, n.d.). This deserves further investigation. Despite challenges identified over 20 years ago (Guralnick, 1981), there continue to be concerns with the physician-educator relationship.

Searching for resources placed a great strain on these 6 mothers. Despite lack of support from some physicians, these mothers were determined to seek out services for their children. Yet, even when the mothers were aware of the possibility of developmental services and made contact with the early intervention program, they continued to run into roadblocks such as waiting lists and lack of providers.

Enrolling in services. We expect babies with typical development to make rapid developmental changes; conversely without interventions, babies who have developmental concerns can fall further and further behind. Therefore, the Individuals with Disabilities Education Act specifies, "within 45 days after it receives a referral, the public agency shall complete the evaluation and assessment activities and hold an IFSP meeting" (Early Intervention Program, 1999). Three of the mothers in the study, Tomi, Suni, and Boni, experienced delays when their children were first referred to early intervention program services. Joni also expressed frustrations about the waiting she encountered in accessing specific developmental therapies.

The problems these mothers encountered with waiting lists are not specific to any one state. Although in direct violation of federal law, there appears to be a trend where it takes longer than the prescribed 45 days to get on evaluation and to commence services. Federal monitoring of state early intervention programs cited problems with the 45-day standard in 46% of states monitored since 1997 (OSEP State Monitoring Reports, n.d.) The mothers in my study experienced stress and frustration while attempting to enroll in services. First, the difficulties in navigating bureaucratic regulations caused anxiety. But, even more, the time lost in providing services to the children was a constant tension in these mothers' lives.

Two factors contribute to problems with the 45-day timeline. First and foremost is the challenge early intervention program managers face in balancing inadequate budgetary resources to effectively serve the growing numbers of children referred for services. Secondary to the initial challenge is finding adequately skilled and trained professionals to fill early intervention positions (McWilliam & Young, 1996). The Twenty-Second Annual Report to Congress on the Implementation of the Individuals with Disabilities Education Act identified crucial personnel shortages that failed to meet the needs of the federal Early Intervention Program. Nationwide, over 3,800 positions were unfilled at the time of the report. Reported shortages included 692 special educators, 405 occupational therapists, 410 physical therapists, and 686 speech-language pathologists (U.S. Department of Education, 2000). Obviously the issue of supply and demand affects states' ability to meet the mandated 45-day timeline for service provision. For the mothers in my study, however, bureaucratic rhetoric regarding staff shortages did nothing to ease concerns regarding delays in enrolling their children in services.

Learning the system. Once enrolled in the early intervention program, the service delivery options these mothers encountered were very limited. Each of the mothers in my study expressed a preference for having services delivered in the family home. Besides the convenience and financial savings involved in not having to transport children to

services, they acknowledged the importance of having skills taught in the environment in which they will be required. Roni, Suni, Tami, and Lori expressed mixed reactions to moving developmental services from the home to an early intervention center. Both Roni and Suni felt concerns over having their children away from home at such a young age. Tomi was uncomfortable with Daniel being provided services in a segregated setting. Lori was not happy with some of the practices she had observed at the early intervention center. At the end of the study, Tomi and Suni's children were both receiving services in an inclusive childcare setting. Lori was also investigating the possibility of moving Megan to Tomi's and Suni's childcare provider.

Although each of these children originally started services with home interventionists, home-based services were only one facet of an array of fragmented services. Each of the 6 mothers transported her child to additional therapies. Tomi and Roni each reported taking their children to see from six to eight different medical and developmental professionals in one week. This model of fragmented service delivery promotes viewing these children from the perspective of pieces, rather than as a whole child.

There also appeared to be an assumption on the part of the early intervention program that by 18 months of age, children should receive services in a segregated early intervention center. This requirement

caused additional guilt and anxiety for the mothers because their very young children were away from home for a substantial portion of the day. Despite the 1997 Amendments to IDEA that requires early intervention program services to be delivered in "natural environments," the emphasis on center-based services persisted. However, Tami and Suni fought this option. They recognized the benefit to their children of associating with typically developing peers and fought for placement in an inclusive child-care setting. Under this model, interventionists came to the child-care setting to deliver developmental services, rather than requiring the family to transport to multiple settings for fragmented services. However, this was the exception. Much more frequently the mothers in this study encountered agency policies that reflected a rigid and limited perspective on models of service delivery.

The legislation governing the federal Early Intervention Program takes a different view of service delivery in their promotion of family-centered service delivery. As part of every IFSP, a service coordinator is assigned to the family. Among the regulated responsibilities of the service coordinator are "coordinating all services across agency lines, serving as the single point of contact in helping parents obtain the services and assistance they need, and facilitating the timely delivery of available services" (Early Intervention Program, 1999). Mothers in this study reported little, if any, coordination between agencies or even between service

providers within a single agency. The participants reported that the responsibility of making connections across agencies was primarily their own. For example, Lori's daughter Megan was receiving speech-language and physical therapy services at both the early intervention center and through private practices that were paid for by insurance. Lori chose this type of service delivery in order to arrange private therapies at a time when she could participate. Although all of the service providers were aware of this density of services, Lori found that any sharing of information across agencies was dependent upon her. These service providers were clearly working under a multidisciplinary model, where the child receives a variety of services but communication among professionals is limited or non-existent. These fragmented services, where professionals were reluctant to release or share discipline specific strategies with one another, were difficult for families and did not best serve the needs of the mothers or children.

Recognizing the need for more coordinated service provision within natural environments, researchers have identified the transdisciplinary Primary Service Provider model as an effective alternative to fragmented services (Bailey et al., 1998; Guralnick, 1997; McWilliam, 2000a). The Division of Early Childhood of the Council for Exceptional Children recognizes this service delivery model as a recommended practice for early intervention providers

Transdisciplinary service delivery refers to professionals from different disciplines working together, with one of them serving as the primary contact with the family. The primary contact uses strategies that other team members provide, and other team members have direct contact with the family only as necessary (e.g., for assessment, for demonstration). (McWilliam, 2000b, p. 51)

Under this model, families receive at least one home visit a week from one primary service provider. This provider works closely with the child's coregivers to enhance the child's developmental progress by encouraging daily interactions with the child during regular routines. Each member of the IFSP team coordinates services through consultation with the primary service provider, occasionally making joint visits to the family home. Families develop a relationship with one service provider. This one provider, then, is in an ideal position to provide the family with both informational and emotional support. It is not surprising, given the participants' reports of fragmented services, that the transdisciplinary model, though recommended, has not yet been implemented in this area of Florida. McWilliam (2000b) indicates that an additional benefit to adopting this model would be the ability of agencies to serve additional children with limited providers. By so doing, it is possible that waiting lists for services could be decreased or eliminated.

Throughout the course of service delivery, mothers constantly evaluated the early intervention program and service providers. At times, these mothers requested to switch service providers to better accommodate the needs of their children or themselves. Often the

mothers made these requests in attempts to receive services that were more family-centered. The last sub-stage encompasses these mothers' reflections and the resultant suggestions they made for early intervention program services.

Looking back. Both Bronfenbrenner's (1979) groundbreaking work on social ecology theory and Turnbull, Summers, and Brotherson's (1984) family systems framework link the family environment to human development. Central to both perspectives is the concept that issues that impact one family member have reflective influence upon other family members. The mothers in my study reported on the influence their children's disabilities had on their entire family system. The legislation governing services to infants and toddlers with disabilities recognizes this impact. Thus, there is substantial documentation for the importance of services to young children with disabilities being delivered via a family-centered approach.

The 6 mothers in my study identified specific service provider characteristics that were important to them, all of which align with a family-centered approach. These characteristics included having proficient skills and positive attitudes. It is important to note that the mothers felt just having skills was not sufficient. Indeed, competence was the minimum expected of any provider working for the early intervention program. What each mother viewed as crucial variables was the attitude

of the provider, both towards the child and the parent. These attitudes contributed to the mothers' perceptions of the service providers' ability and willingness to provide family-centered services. Thus, a critical component of the child's interventions became the way these mothers were welcomed and included as part of the intervention process. Clearly, these mothers desired partnerships with the service providers.

These mothers also expressed multiple concerns for the attitudes and service delivery methods of medical personnel. Although these concerns permeated the time from their children's birth through the end of the mothers' participation in the study, concerns were particularly expressed regarding the manner in which their children's diagnoses had been delivered. Due to their children's disabilities, these mothers were involved in medical settings more frequently than parents of typically developing children. Four of the children had substantial medical histories involving multiple surgeries. Of note is the fact that 5 of the mothers had experience working in medical settings; Boni as a financial analyst for a large medical center, Rani as a medical transcriptionist, Suni as a recreational therapist, and Joni and Tami as nurses. Despite their medical backgrounds, Joni and Tami both reported that their interactions with medical providers were often unsatisfactory. Remarkably, they were treated as having a lower level of competency when seen as mothers versus the time they interacted with the same medical professionals in a

nursing capacity. The traditional medical expert versus patient relationship dominated medical interactions for these mothers. It is clear that these mothers who had experienced components of family-centered partnerships in collaborating with developmental service providers, also sought collaborative interactions with their children's medical providers. Regardless, the insensitivities reported by these mothers as they detailed interactions with doctors should not be tolerated.

Within Bronfenbrenner's (1979) social ecology theory, interactions between these mothers and their children's service providers would be represented as mesosystem connections. The 6 mothers in my study made abundantly clear that the quality of these interactions directly affected the quality of the service to the children. Indeed, these mothers sought to be actively involved in their children's therapies. Those service providers who recognized the importance of family-centered services were more effective with the child and family. Of the 7 service providers observed and interviewed, only 1, Dana, appeared to display a reluctance to fully partner with the mothers. Minke and Scott (1995) indicate that some providers may experience doubts about whether all parents have the necessary skills for full participation. Yet federal legislation specifies that services should be provided to meet the needs of children and *their families* (Early Intervention Program, 1999). The law, then, encourages service providers to support family members in their

ability to participate fully as team members. Additionally, the Division of Early Childhood of the Council for Exceptional Children's Recommended Practices indicates "supports and resources provide families with information, competency-enhancing experiences [emphasis added], and participatory opportunities to strengthen family functioning and promote parenting knowledge and skills" (Sandall, McLean, & Smith, 2000, p. 45).

Two service providers, Anna and Gina, recognized the professional benefit they obtained by listening to and incorporating family members. Their practices reflected family-centered methods that went beyond just releasing their role to the parents by suggesting or assigning specific skills that could be practiced within the home environment. They acknowledged the reciprocal benefit that they, as service providers, received from the mothers, which heightened their own effectiveness in working with children. DEC Recommended Practices recognize that "[Family-centered] practices, supports, and resources promote the family's and professional's [emphasis added] acquisition of new knowledge and skills to strengthen competence and confidence (Sandall, McLean, & Smith, 2000, p. 46).

I propose three variables that might contribute to a service provider's adoption of a true family-centered model of practice. First, Anna and Gina, the two practitioners who openly acknowledged the reciprocal benefit they received from using this approach, had both been

involved in providing early intervention program services for over 20 years. Thus, experience in providing services using a family-centered approach can contribute to providers embracing this philosophy. Second, beginning service providers, regardless of discipline, need family-centered strategies taught in their pre-professional programs. Early childhood special education training programs typically provide a focus on family-centered models of service delivery. Professionals who are trained to engage in reflective practice regarding interactions with families are in a good position to recognize the reciprocal benefits they receive as they actively engage parents as partners in the therapy process. Also, they begin gaining valuable experience in using a family-centered approach while in training. Third, current training in these methods should not be restricted to pre-professional programs. The literature is replete with the need for ongoing professional development in family-centered practices (Boiley, Buysse, Smith, & Elom, 1992; Granlund & Bjorck-Akesson, 2000; McCollum, 1994) yet the service providers interviewed as part of this study reported that training was inconsistent. It is incumbent upon early intervention program administrators to insure that all service providers, regardless of the length of their service, be schooled in the application of these approaches through ongoing professional development.

One might question whether policies and philosophies of agencies matter in family-centered services. Indeed, in my study various service

providers working for the same agency reflected different interpretations of family-centered services. Yet in order to promote family-centered practices, early intervention programs must have firmly established policies that support a clearly defined mission to deliver family-centered services (McWilliam et al., 1995). Furthermore, these programs must require not just training, but active practice of these approaches. It is only through guided practice and evaluation that all providers can have the opportunity to develop and broaden the attitudes that form the basis of family-centered services. Indeed, in a study of how service providers constructed the meaning of family-centered services in early intervention programs, McWilliam and colleagues (McWilliam, Tocci, & Harbin, 1998) identified five underlying components of family-centered services including (a) positiveness, (b) sensitivity, (c) responsiveness, (d) friendliness, and (e) child and community skills. It is noteworthy that four of these five components represent attitudes rather than skills, and that in fact, "child and community skills" are methods that grow directly out of the first four attitudes.

Of equal importance is the recognition that, regardless of the philosophy of the agency for which they work, many related service providers are trained in programs with little or no reference to families' involvement in therapy services. During interviews, Becca and Fanda both referred to training that treated the home as a separate context for

skill generation in children with disabilities. Such training fosters the belief that connections between therapy services and home should be restricted to assignments to promote generalization of skills. It seems apparent that a true recognition of the benefit of family centered services was not a component of these service providers' pre-professional training. Although Anna too had not received any training regarding family-centered services, her own desire for professional development motivated her to learn more about early childhood special education through university coursework. However, service providers should not be expected to take such initiative without support (i.e., tuition reimbursement, release time) from their agencies.

Limitations

This study generates information regarding 6 mothers' experiences of coping with an initial diagnosis of disability and accessing early intervention services during the crucial developmental period from birth through 2 years of age. A limitation to my study is that, though I utilize a family systems framework, I did not directly study all components of each family. I chose to focus on mothers because traditionally they serve as gatekeepers to early intervention services, but the fact that I only interviewed mothers and only their perceptions are represented limits the possible applications to family systems theory. One cannot assume that the opinions and experiences of these mothers represent those of the

fathers, siblings, or other family members impacted by the child's disability. To completely reflect family systems theories, the views of all family members should be considered.

Another related limitation is the fact that these mothers only represent one ethnicity, one class, and one locality. It is possible that the characteristics of these mothers influenced the outcomes of my study. All of the participants were Caucasian, educated, middle-class mothers residing in central Florida. Five of the 6 mothers had work experience in medical settings. Although Tomi's and Lori's children received initial services in other states, the bulk of all the mothers' experiences were specific to Port C early intervention program policy interpretations in central Florida. Again, one cannot assume that the opinions and experiences these mothers have in common represent those of other ethnicities, educational levels, social classes, or geographical locations.

Further limitations stem from the possibility that interview questions may not have adequately prompted or stimulated discussion around all the aspects of family systems. First, the mothers may have felt restricted to only share past experiences. There were limited concerns expressed for the children's futures. Those mothers who were looking ahead to future events reported more imminent activities, such as the children's transitions into preschool services. Although I asked about specifics of the children's disabilities, only two of the mothers, Roni and Joni, mentioned implications

of their children's disabilities in the distant future. The second negative finding is the silence regarding the role the fathers play. One question, asking the specifics of the spouses' reaction to the disability diagnosis, might have prompted descriptions of the fathers' participation. Specific inquiry or further probing might have revealed more substantial information regarding their involvement.

Finally, the limited timeframe during which these mothers and children were involved with the early intervention program may also limit this study. Because the study was focused exclusively on the first 3 years of a child's life, only 2 of the 6 participants were involved throughout the duration of the study. Although the 4 other mothers were each interviewed and/or observed between 3 and 5 times, extending the data collection over a longer period of time might have contributed to the depth and breadth of the findings. Though more suggestive than conclusive, the experiences and reflections of these 6 mothers provide an important foundation and impetus for future research examining the early period of families' adjustments to a child's disability.

Implications for Future Research

My findings suggest many important and necessary directions for future research. A similar study should be done interviewing and observing fathers and/or siblings in order to compare their perceptions and experiences with the mothers in my study. Do family-centered

services carry the same importance for other family members as these mothers reported? Can service providers better serve fathers' emotional, spiritual, and informational needs? Inasmuch as family-centered services are a major component of the federal Early Intervention Program, studies of this kind would contribute to practitioners' ability to anticipate and respond to the needs and concerns of the entire family system.

It is equally important to extend this type of study to families of other ethnic and socioeconomic backgrounds living in a variety of states. Once again, the perceptions and desires of these families may differ from the mothers in this study. Increasing the research base to include a more culturally diverse population would help ensure that the methods service providers use are culturally responsive rather than based on unconscious assumptions and potentially harmful biases. Quantitative research methods would serve to determine the generalization of these findings to a larger, more diverse population.

More research is needed on the link between families' use of palliative and adaptive coping strategies. As I have reported, each of the participants depended to some degree on palliative strategies to buy themselves time to adjust to having a child with a disability. Though research has shown that palliative coping strategies are not as effective in dealing with long-term stressors as adaptive strategies, most people seem to respond first to extreme stressors with palliative strategies. Could

training and supports be provided to families upon informing them of a child's diagnosis of disability in order to increase their awareness of palliative coping? Would this decrease the duration and intensity of their reliance upon these less effective strategies and hasten their shift to problem-solving adaptive techniques? My research suggests this may be the case, but further study is needed.

Finally, it is important to continue to study the philosophies and actions of service providers relative to family-centered services. These 6 mothers unanimously desired attitudes that reflected a family-centered approach, so we must now ask: What types of training succeed in infusing a family-centered philosophy and corresponding methods across disciplines, especially into those that have traditionally followed a medical model of service delivery? What system-wide requirements placed on licensure and certification of all service providers would ensure that a family focus is implemented across early intervention agencies? Research into the effectiveness of various possible procedure changes is needed in order to decide how best to implement the suggestions these mothers—and other future study participants—have for policy makers and service providers.

Recommendations for Practice and Personnel Preparation

My study revealed that policy makers and service providers are in a position to alleviate many of the challenges facing families of infants and

toddlers with disabilities. The following recommendations are based on what these 6 mothers perceived as appropriate and effective intervention strategies for working with families.

Recommendations for Practice

These mothers all felt it is imperative that program coordinators recognize the supports that need to be in place when diagnoses are delivered. All mothers reported feeling confused about how to access services, and two expressed strong sentiments regarding having counseling supports available at the time diagnoses of significant disabilities are given. Even physicians were unsure of the most direct avenue parents should pursue. These deficiencies cannot be ignored. There must be an increase in awareness of early intervention program services, both on the part of medical personnel and the general public. Medical personnel can be educated through better training procedures, which I iterate below; the general public should be reached through statewide public education campaigns. Last, delays in provision of services following initial referral for evaluations cannot be tolerated indefinitely. Whether through reassignment of service providers, reallocation of funding, increases in funding relative to the growing numbers of children requiring services, or all of the above, services must start being provided in a timely manner as dictated by law.

Recommendations for Personnel Preparation

In order for these mothers' suggestions to be implemented in the practice of policy makers and service providers, the means by which personnel are trained to provide services must be enhanced. For this reason, I recommend that early intervention program administrators ensure that all service providers, regardless of discipline (i.e., occupational therapy, physical therapy, speech-language pathology), are rigorously trained and monitored in their provision of family-centered methods. Alliances should be made between university early childhood special education programs and medical schools and allied health colleges. During the study of child development, medical students and pre-professionals in occupational therapy, physical therapy, and speech-language pathology need to be made more intimately aware of the mitigating factors that can contribute to developmental disabilities. They must not only be informed of the early intervention program, but also understand how vital it is to make timely referrals. Finally, components of family-centered services including positiveness, sensitivity, responsiveness, and friendliness must be incorporated as *requirements* of training, not simply as the niceties of bedside manner.

Also, because the mothers' suggestions for early intervention program services mirrored adoptive coping strategies, it is important that policy makers and all service providers be thoroughly trained in such

coping techniques. With this training, policies that dictate how services are administered, as well as the techniques used in providing services, can better facilitate a family's transition from less-effective palliative coping to problem-solving strategies such as reframing, seeking information, and creating a support system. These changes in current personnel preparation procedures would not only benefit children with disabilities and their parents, but the medical, allied health, and special education personnel would be able to carry out their tasks more easily and effectively.

Summary

The Individuals with Disabilities Education Act requires that agencies and interventionists include family supports as part of Individualized Family Service Plans. But what do we really know about the needs of individual families? Have we asked them? Not nearly enough. In this study I began doing exactly that, and the 6 mothers of infants or toddlers with disabilities whom I interviewed revealed many shared experiences and reactions. Though the patterns that emerged across the 6 participants are more suggestive than conclusive, we cannot ignore these mothers' anguish when hearing a diagnosis, the loneliness when their expectations for the future tacitly shift, their frustration over trying to navigate the system, and their longing to interact with service providers who are sympathetic and supportive toward families. These mothers' responses have clearly

established the negative impact of service practitioners who are not sensitive, informed, or family-focused. Their message is clear: strengthen the implementation and increase the availability of family-centered services.

My findings indicate several important steps that need to be taken. More research is needed concerning the perceptions and experiences of other family members and families from a variety of ethnic, socioeconomic, and geographic perspectives. These responses could then be combined with those of the 6 mothers in my study to give practitioners and theorists a more complete view of what it is like for different families to cycle through the sub-stages of (a) becoming aware of a child's diagnosis of disability; (b) discovering, seeing, and finding services; (c) enrolling in services; (d) learning the system; and (e) looking back. Fortified with this information, the extent to which the patterns identified among these 6 mothers also occur in other populations can be determined, and additional patterns may be identified.

It is important that research inform practice. The data collected from these mothers strongly indicate that family-centered services are the most effective and the first choice of mothers of children with disabilities. This reaffirms what Bailey and colleagues (1998) and Guralnick (1997) have shown to be true. The difference is that these women have told us about the extra stress they and their families go through because we are

not doing enough. One family relocates across the country in order to gain access to programs. A child languishes without services while waiting for a referral. Many stunned, grief-stricken parents hunt unassisted for information that will help their baby. Their stories are numerous—and there are more out there—but we can take steps now to improve the training of medical and educational service providers.

It does no good for agencies to have family-centered philosophies if their policies and service providers do not consistently reflect and implement this approach. Service providers can do more to aid parents of children with disabilities in developing adaptive coping strategies, and better training can show them how. Medical personnel can affect the entire future of an infant with disabilities, and the family, by being better prepared to give prompt referrals and information regarding the early intervention program. Both on-going and pre-professional training across disciplines can begin cultivating a greater awareness and understanding of family-centered approaches and how they extend into the educational and medical settings outside the home. With this deeper understanding of the sub-stages of the early childhood life cycle, we who are involved with the diagnosis and treatment of children with developmental disabilities have more cause than ever to believe that we can make a real difference in these children's and families' lives.

APPENDIX A
INTERVIEW QUESTIONS—PILOT STUDY

1. It would help me to know some things about you. Would you tell me about your family?

What about your family of origin?
2. Did you know any children with disabilities when you were growing up? Could you explain your relationship with them? What were your feelings about disability at that time?
3. Tell me about (child)'s disability.
4. Tell me about a typical day with (child).
5. Tell me about when you first realized that (child) had medical or developmental problems.
6. Who explained these problems to you? Tell me about that experience.
7. What were your supports during that initial time of finding out about the disability?
8. What information did you receive about the disability? Who provided that information? Was it adequate? What other resources have you been offered or have you used to find out more?

9. What do you think may have caused (child)'s disability?
10. Tell me about the reaction of others to your child's disability
 - Spouse
 - Siblings
 - Grandparents
 - Friends
11. When did your child first start receiving services? What were those services? Who provided those services?
12. Can you tell me about the services (child) and your family are presently receiving? How do you feel about those services?
13. If you could make a change in the services (child) and your family has received, what would you like to change?
14. Having a child with a disability can be a very stressful situation. Have there been times that have been unusually difficult for you? How did you manage during that time?
15. What do you turn to for support during these times?
16. Have there been people who have been especially supportive to you?
17. Has there been a service provider that has been especially helpful to you and your family? How was this person helpful? What made this person different from others with whom you have worked?

18. What kinds of social and emotional supports are you receiving?

From whom?

APPENDIX B
INTERVIEW QUESTIONS—REVISED

1. It would help me to know some things about you. Tell me about your family.
What about your family of origin?
2. Did you know any children with disabilities when you were growing up? Explain your relationship with them. What were your feelings about disability at that time?
3. Tell me about (child)'s disability.
4. Tell me about a typical day with (child).
5. Tell me about when you first realize that (child) had medical or developmental problems?
6. Who explained these problems to you? Tell me about that experience.
7. What were your supports during that initial time of finding out about the disability?
8. What information did you receive about the disability? Who provided that information? Was it adequate? What other resources have you been offered or have you used to find out more?

9. What do you think may have caused (child)'s disability?
10. Tell me about the reaction of others to your child's disability.
 - Spouse
 - Siblings
 - Grandparents
 - Friends
11. When did your child first start receiving services? What were those services? Who provided those services?
12. Tell me about the services (child) and your family are presently receiving? How do you feel about those services?
13. If you could make a change in the services (child) and your family have received, what would you like to change?
14. Having a child with a disability can be a very stressful situation. Describe times that have been unusually difficult for you?
15. How did you manage during stressful times?
16. What kinds of social and emotional supports have you received?
17. Have there been people who have been especially supportive to you? Who have they been?
18. Has there been a service provider that has been especially helpful to you and your family? How was this person helpful? What made this person different from others with whom you have worked?

19. What kinds of social and emotional supports are you currently receiving? From whom?
20. Tell me about any positive experiences you or your family has had as a result of your child's disability.

APPENDIX C
SERVICE PROVIDER INTERVIEW QUESTIONS

1. Tell me about the training you received for your present position.
2. Which, if any, of your courses involved perspectives of family involvement?
3. What is the policy of your agency regarding family involvement?
4. What training has been offered through your agency supporting family involvement?
5. In what ways do you incorporate family involvement into your therapies?
6. What do you personally feel are the benefits of family involvement in the therapy process to the child's development?
7. What do you personally feel are the disadvantages of family involvement in the therapy process?
8. Summarize your philosophy of family-centered services.

APPENDIX D
WAYS OF COPING QUESTIONNAIRE

Ways of Coping

Below is a list of ways people cope with a wide variety of stressful events. Think about how you dealt with a recent difficult situation. For each statement below, please circle the number that applies to you.

	Not Used	Used Somewhat	Used Quite A Bit	Used A Great Deal
1. Stood my ground and fought for what I wanted.	0	1	2	3
2. Made light of the situation; refused to get too serious about it.	0	1	2	3
3. I tried to keep my feelings to myself.	0	1	2	3
4. Talked to someone to find out more about the situation.	0	1	2	3
5. Criticized or lectured myself.	0	1	2	3
6. Wished that the situation would go away or somehow be over with.	0	1	2	3
7. I knew what had to be done, so I doubled my efforts to make things work.	0	1	2	3
8. Changed or grew as a person in a good way.	0	1	2	3
9. Tried to get the person responsible to change his or her mind.	0	1	2	3
10. Went on as if nothing had happened.	0	1	2	3
11. Kept others from knowing how bad things were.	0	1	2	3
12. Talked to someone who could do something concrete about the problem.	0	1	2	3
13. Realized I brought the problem on myself.	0	1	2	3
14. Hoped a miracle would happen.	0	1	2	3
15. I made a plan of action and followed it.	0	1	2	3
16. I came out of the experience better than I went in.	0	1	2	3
17. I expressed anger to the person(s) who caused the problem.	0	1	2	3
18. Didn't let it get to me; refused to think about it too much.	0	1	2	3
19. Tried not to burn my bridges, but leave things open somewhat.	0	1	2	3
20. I asked a relative or friend I respected for advice.	0	1	2	3
21. I made a promise to myself that things would be different next time.	0	1	2	3
22. Had fantasies about how things might turn out.	0	1	2	3
23. Just concentrated on what I had to do next – the next step.	0	1	2	3
24. Found new faith.	0	1	2	3

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BIOGRAPHICAL SKETCH

A native of southeastern Idaho, Ann Bingham was raised on a dairy farm with three sisters and three brothers. There she learned the value of hard work, applied both in the classroom and in responsibilities on the family farm. Following high school graduation, she completed two years of study in special education at Brigham Young University before leaving school to marry and raise a family.

Eighteen years and four children later, Ms. Bingham again entered the university classroom, this time as a non-traditional student. In 1993, she earned a B.S. in speech pathology and audiology from Idaho State University. She stayed at Idaho State to complete dual master's degrees in 1995 (M.S. in speech-language pathology and M.Ed in human exceptionality, early childhood special education emphasis). She was subsequently employed by the state of Idaho as a speech-language pathologist in the Part C early intervention program, providing services to infants and toddlers with disabilities and their families. Through an interagency agreement, Ms. Bingham also served preschool children in both segregated and inclusive classroom settings. During this time, Ms. Bingham served as adjunct faculty at Idaho State University, supervising speech-language pathology intern students. She also participated as a

member of the Idaho Interagency Coordination Council for the Part C early intervention program.

1998 brought opportunity for further education as Ms. Bingham was recruited into the doctoral program at the University of Florida. During her doctoral program, she supervised practicum and intern students in the unified general and special education early childhood program, worked as a research assistant on several projects, and taught classes in both the Unified Early Childhood Program and Unified Preteach.

In 2001, Ms. Bingham accepted a tenure-track position at the University of Nevada, Reno. Besides continuing research that addresses family issues, she plans to study how and when special education preservice students developed attitudes directing them towards disability issues.

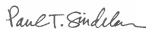
Ms. Bingham lives in Reno with her daughter Amilynn, an English education student at the University of Nevada. She enjoys day trips to Lake Tahoe, sports, reading, and traveling. Future travel plans include visits with her daughter Melissa, a high school Italian and art history teacher in Richmond, Virginia, and sons David, a Ph.D. student in astrophysics at The Ohio State University, and Alan, a pre-law student at Brigham Young University—Idaho.

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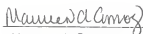
Vivian I. Correa, Chair
Professor of Special Education

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Paul T. Sindelar
Professor of Special Education

I certify that I have ready this study and that in my opinion it conforms to acceptable standards of scholarly presentation and is fully adequate, in scope and quality, as a dissertation for the degree of Doctor of Philosophy.



Maureen A. Conroy
Associate Professor of
Special Education

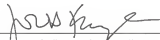
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Rodman B. Webb
Professor of Educational Psychology

This dissertation was submitted to the Graduate Faculty of the College of Education and to the Graduate School and was accepted as partial fulfillment of the requirements for the degree of Doctor of Philosophy.

May 2003



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